A USER'S MANUAL FOR THE ENFORCED SOCIAL DEPENDENCY SCALE

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A User's Manual for the Enforced Social Dependency Scale

Introduction

Cancer is considered catastrophic in nature because it necessitates major changes in the living pattern of adults with cancer. Such changes are characterized by physical alterations in the body that over time impinge on the patient's ability to function as a normal social being and lead to a state of enforced social dependency. These changes can occur as a result of the disease, treatment, or a combination of both. Changes brought on by the treatment may be temporary, such as enduring fatigue or permanent, such as an amputation. Also, changes in function are affected by the stage of the disease. In early stage cancers, the change is directly related to the treatment, but in late stages cancers, the changes are cumulative and are related to both the treatment and a progressive disease. Eventually, as the disease progresses, the patient may become dependent on others for intimate functions not ordinarily performed by other people except during early childhood. In addition, during cancer treatment and especially with advanced disease, distressing symptoms accompanying changes in function. Regardless of the source of discomfort, reliance on other people is common and becomes a central characteristic of the cancer patient's situation. Such enforced social dependency threatens the person's independence or autonomy and potentially may decrease one's sense of power, control, and self-esteem. Not only does this increased dependency impinge negatively on the patient's self-esteem, but also social relationships may be dramatically altered. Difficulties of interpersonal relationships resulting from pain or other symptoms can be aggregated by the position of social dependency. This kind of enforced dependency can further contribute to reactivation of all manners of unresolved problems in living and in the patient's relationships with other people.

A major goal of health care is to assist individuals to maintain or regain their pre-illness level of function or to attain the maximal functional level possible given their current health status, and subsequently to improve quality of life (O'Boyle & Waldron, 1997; Schipper, 1992). However, predictive measures to identify the coping capabilities of cancer patients and their families in managing the patient's increased social dependency have been slow to emerge. Little is known about the coping mechanisms used by cancer patients and their families who deal effectively with the declining functional status as the disease progresses. In order to achieve the identified goal of health, one of the first steps necessary in defining functional status was the establishment of criteria to judge a person's abilities to perform the activities and tasks normally expected of an adult and the actual performance of that person's role functions.

Instruments that measure function can assist health professionals in both the research and the clinical arenas. In research, the use of valid and reliable instruments to measure function is critical for the development of an empirically based body of knowledge concerning the outcomes of clinical interventions (Richmond, McCorkle, Tulman & Fawcett, 1997). Clinically, systematic identification of functioning which may be disrupted by disease or treatment can allow for planning and implementing appropriate clinical interventions at crucial times to assist cancer

patients to adjust to the changes in the performance of their usual activities, to facilitate their performance of new cancer or treatment-related activities, and to promote their optimal functioning during the entire trajectory of cancer disease. In addition, assessment of cancer patients' functional status provides a baseline for outcome evaluation of nursing and medical interventions (Fawcett & Tulman, 1996). Furthermore, in a cost-containment era, functional status can be recognized as a primary indicator of the time needed to complete selected nursing care. As patients' functional status change, the requirements for nursing care change. Therefore, accurately assessing functional status of patients also contributes to the adequacy and composition of staff and allocation of resources for institutional settings (Willard, 1990).

Developing reliable, valid, and useful instruments for evaluation of function has been receiving increasing attention since the mid-1970s. The purpose of this manual is to describe the development of a scale that will allow health care providers to assess levels of social dependency in patients with cancer across the cancer trajectory and help health professionals make appropriate changes in clinical care to accommodate the needs of patients. The manual consists of three chapters and four appendices. The first chapter provides the definition of function and illustrates the historical development of the enforced social dependency scale (ESDS), method of administration, and scoring procedures for the ESDS. The use and advantage of the ESDS, as well as the differentiation of ESDS with other available functional assessment tools, are discussed. The second chapter presents information about the psychometric properties of the ESDS from a variety of perspectives. In addition, summary data from published and previously unpublished studies about the psychometric properties of the ESDS are presented in a tabular format to enable users to compare results of the ESDS scores obtained in their samples with the ESDS scores obtained in similar samples. A summary of the use of the ESDS in various studies, suggestions for future research, and information about obtaining the ESDS are provided in chapter three. The final section of this manual, the appendices, include an annotated bibliography of published studies that used the ESDS, the two interview guides for evaluating the patient's functional competence, and coding instructions for the ESDS.

Chapter 1

Overview of the Enforced Social Dependency Scale

The Concept of Function

The concept of function has been defined in various ways. The terms function, functioning, functional ability, functional status, physical function, level of impairment, disability, handicap, and health status are frequently used interchangeably. Lack of clarity concerning the concept of function and its definition has resulted in making comparisons across studies and integration of findings difficult. What is needed is a common language and standardized tools to compare the assessments of functional status and results of clinical interventions targeted at changing functional status (Richmond, McCorkle, Tulman & Fawcett, 1997).

Richmond, McCorkle, Tulman and Fawcett (1997) defined *function* as "how people perform activities that are relevant to personal expectations and social norms". The concept of function incorporates both the ability to perform activities or tasks that are important for independent living and the actual performance of activities and tasks crucial to the fulfillment of roles within one's current life circumstances. Function is viewed as a concept with two dimensions: functional ability and functional status.

Functional ability refers to the actual or potential capacity to perform the activities and tasks normally expected of an adult.

Functional status refers to individuals' actual performance of activities and tasks associated with their current life roles. Limitations in functional status occur when there is a discrepancy between individual performance and average expectable role performance.

Enforced social dependenye is defined as the state in which patients require help or assistance from others in performing activities or roles that under ordinary circumstances adults can perform by themselves. Under ordinary circumstances in society, adult human beings who are not handicapped by disease or injury are socially independent creatures in the sense that they have considerable choice about entering into a state of dependency on other people. This state of dependency refers to a situationally required state of reliance on other persons for help with activities ordinarily carried out by the individual. Enforced social dependency is a state (an aspect of the individual's current situation) rather than a trait (an enduring characteristic of the individual). It is a response to the current situation, not an inherent characteristic of the patient.

Process of the Development of the Enforced Social Dependency Scale

1. Determining appropriate items and scaling methods

A pilot study by McCorkle in 1976, "***Identification of human concerns in patients with cancer***", revealed that self-care, social, and mobility problems were major concerns of patients with cancer. At the same time, this study brought to light that existing tools for measurement of functional status did not have uniform scoring methods across items and were unsuited for the types of information needed for an overall measurement of dependency in patients with cancer. The decision was made to develop a more specific scale addressing the three major problem areas identified by patients in the pilot study. Collection of data for this tool development was done through subject interviews.

The next step in the development for the ESDS was selection of valid items. Selection of items that represent the construct being measured is critical when developing a new instrument. Inappropriately selecting representative items renders an instrument invalid for its intended purpose. Items selected for the ESDS characterized three concepts, or three capacities which included everyday self-care competence, mobility competence, and social competence. Concurrently, a panel of patients with chronic illnesses validated these capacities as being necessary for an adult's performance of usual and expected roles. The construct of social dependence was defined as the absence of these basic competencies or at least diminished capacity for one or more of them.

Everyday self-care competence

The degree of everyday self-care competence was defined as the degree to which the patient was able to take care of ordinary tasks of daily living without direct assistance from others. The four activities judged central to performing as a normal adult were: (a) bathing, (b) dressing, (c) eating, and (d) toileting.

Mobility competence

The degree of mobility competence was defined as the degree to which the patient was able to move about without direct assistance from others and without the need for special equipment. The four activities judged central to performing as a normal adult were: (a) walking, (b) stair climbing, (c) transferring, and (d) traveling.

Social competence

The degree of social competence was defined as the degree to which the patient was capable of communicating with others in regard to goals, wishes, and personal needs. As a concept, social competence involved various kinds and levels of activity, including being able to talk, to initiate activity with others, to perform alone, to perform in collaboration with others, to assume usual roles, and to meet other social obligations and expectations. The four variables judged central to performing as a normal adult were: (a) consciousness, (b) role activity, (c) social interaction, and (d) social interest. Consciousness related to awareness of self-identity and location and awareness of situations with reference to time, place, and identity of persons. Role activity was defined as the subject's routine work and social activities, including hobbies. Social interaction referred to whom the subject was interacting with and where. Social interest included the subject's interest

in outside events, others, family, friends, and self.

Conceptually, social dependency was defined as a construct that involved three concepts. Operationally, social dependency was defined as the sum of the individual scores for (a) everyday self-care competence, (b) mobility competence, and (c) social competence subscales. Each subscale had three items, which was coded on a Likert-type scale from 1 to 5, with higher scores reflecting greater enforced dependency.

2. Preliminary test

Initially, the instrument was tested on 10 adults receiving active treatment for cancer in an ambulatory care clinic. Half of the participants were women and half were men. The subjects were asked standardized questions related to each concept. The responses were coded according to pre-established coding categories that represented competence levels on a Likert-type scale from 1 to 5. Inter-rater reliability was not determined in this preliminary test because of the number of instruments tested in the complete battery and the sensitive nature of the questions. This decision was made because the researchers considered that recording bias was less of a risk than response bias.

From the analysis of this preliminary testing, it became apparent that more sensitivity to the degree of the subjects' social dependency was needed. The original five levels of measurement were sensitive to major differences for hospital patients but were not sensitive enough to capture subtle changes that occurred in patients receiving ongoing therapy for progressive disease as outpatients. As a result, the scores for each possible range of activity were expanded from 1 to 6.

Determinations regarding the final selection of items and ranges of behaviors to be described were made after the preliminary testing of the instrument and after a group of experts in the field of cancer nursing had verified this judgment. Following these modifications, the instrument was considered to have face and content validity.

Scores were recorded for each group of activities underlying the three concepts, with a range from 4 at the independence end of the continuum to 24 at the dependence end. Scores on all three competence levels of the ESDS were summed, ranging from 12 to 72.

3. Pilot test

Following the preliminary testing of the instrument, a convenience sample of 60 subjects with advanced disease participated in the pilot test from the radiation oncology clinic and the medical clinics within a university hospital medical center to further explore the reliability of this instrument. In the sample, there were 30 men and 30 women. The majority of subjects were between the ages of 50 and 69 years (62%), married (65%), and living with someone (77%). Most (87%) had cancer while the remainder had a medical diagnosis of another nature.

A single interviewer questioned the majority of the subjects, although one additional person was used on occasion when the primary interviewer was unavailable. There was 95% interrater reliability for all items. The scores, reliability coefficient, and corrected item-total correlations of total social dependency and the three subscales are displayed in tables 1 through 3:

Table 1. Scores of the Enforced Social Dependency Scale in Pilot Test

Scale	Range	Possible scores	Mean	Mode	Median
Enforced Social dependency	12~52	12~72	22	12	18
Everyday self-care competence	4~17	4~24	6	4	4
Mobility competence	4~21	4~24	8	4	6
Social competence	4~19	4~24	9	4	8

Table 2. Reliability test of the Enforced Social Dependency Scale in Pilot Test

Scale	Reliability coefficient	Standardized-item alpha
Enforced Social dependency	0.90	0.91
Everyday self-care competence	0.79	0.82
Mobility competence	0.82	0.87
Social competence	0.78	0.83

Table 3. Corrected item-total correlations of the Enforced Social Dependency Scale in Pilot Test

Scale	Range	Mean
Enforced Social dependency	0.40~0.83	0.65
Everyday self-care competence	0.43~0.77	0.66
Mobility competence	0.53~0.83	0.73
Social competence	0.54~0.83	0.66

Results from the correlation matrix for the activities represented in the ESDS showed that over half of the items had zero-order correlations (r) of approximately 0.41 or above. All correlations were positive. With an increase in enforced social dependency on one item, there was also an increase in social dependency on the other.

There were higher zero-order correlations (> 0.60) for the following: bathing with dressing, walking, and stair climbing; dressing with toileting, walking, and traveling; toileting with walking and stair climbing; walking with stair climbing; toileting with walking and stair climbing; walking with stair climbing, transferring, traveling, and role activity; stair climbing with traveling and social interaction; social interaction with social interest.

The reasons for the higher correlations on the aforementioned items were not clear. Further examination of the relationships between several selected measures of social dependence scale suggested a cyclic effect that may have been generated when a patient lost independence in regard to one or more activities.

The majority of subjects with high scores were rated highest for social competence, then mobility competence, and finally everyday self-care competence. A chronic disease such as cancer limits the patient's ability to take an interest in others and to socialize before it affects the ability to get around and perform self-care. The findings also demonstrated that a greater percentage of subjects with metastatic disease (45%) scored higher on one or more items than did subjects with localized or regional primary tumors (33%).

4. Revision of enforced social dependency scale

The ESDS was further tested and refined in a study conducted by McCorkle and Benoliel (1981). The study was designed to determine how successfully patients cope with one of two chronic diseases (cancer or heart disease) and its consequences. Sixty-one cancer patients and fifty-two myocardial infraction (MI) patients were recruited in this study. The following revisions were made: two mobility items from the original scale were eliminated on the basis of high correlations among items. The remaining mobility items were combined with the self-care items under the category of personal competency. The category of personal competence was now comprised of six activities judged central to performing as a normal adult: eating, dressing, walking, traveling, bathing, and toileting. Each activity was coded on a 6-point Likert-type scale. Scores for personal competence were summed, ranging from 6 to 36.

Content areas for social competence remained the same: level of consciousness, role activity, role interest, and role contact or interaction. Three specific roles were included: spouse, work and recreational roles. The social competence scale at this stage contained eleven activities judged central to performing as a normal social adult: consciousness, attentiveness and memory, activity with spouse, interest in spouse, contact with spouse, work role activities, work role interest, social contact with work associates, recreational and social activities, interest in recreation and socializing, and social contact in recreation and socializing. Scores for social competence ranged from 11 to 43. Scores on the total ESDS ranged from 17 to 79.

During subsequent field-testing, three items were deleted from the social competence subscale. Consciousness was deleted because there was no variance on this item. Items of interest in spouse and contact with spouse were deleted because they correlated negatively with other items. Increased dependency was associated with more time at home, which increased contact with, and possibly interest in, the spouse. The term spouse was also deleted and changed to role because many of the subjects were unmarried. In addition, factor analysis confirmed two unique factors in the ESDS: personal and social competence. Based on the results of this study, the ESDS was revised again. The revised ESDS in this study contained two subscales and 14 items. The range of the revised scale was 14 to 68.

McCorkle and Benoliel (1981) reported reliability coefficients for the total scale by disease groups (alpha= 0.84 for cancer and alpha= 0.80 for heart disease) and one-month test-retest correlations of 0.62. Increased dependence was associated with fewer social activities, including changes in the role responsibilities at home, work, and social activities with others. Scores for cancer and MI patients at both interview waves were displayed as follows:

Table 4. Scores of the Enforced Social Dependency Scale at Revision of the Scale

Disease and occasion	N	Range	Possible scores	Mean	SD
Cancer post-diagnosis one month	61	14~55	14~68	25.0	6.2
MI post-diagnosis one month	52	14~58	14~68	26.7	5.6
Cancer post-diagnosis two months	61	14~57	14~68	25.1	7.8
MI post-diagnosis two months	52	14~54	14~68	22.5	5.8

5. The final version of the ESDS

The ESDS scale has undergone a final revision based on data obtained from a randomized clinical trial (McCorkle, Benoliel, Donaldson, Georgiadou, Moinpour & Goodell, 1989). This study was designed to test the effects home nursing care for patients with progressive lung cancer during which the subscale of personal competence has remained the same. The category of personal competence is comprised of six activities. Each activity is coded on a 6-point Likert-type scale. Scores for personal competence are summed, ranging from 6 to 36. Three specific role activities are included in the social competence subscale: activities in the home, work activities, and social and recreational activities. A fourth behavior related to communication is included. Each role activity is coded on a 4-point, Likert-type scale. The communication competence is coded on a 3-point scale. Social activity and consciousness ratings are summed to produce a score for social competence, which can range from 4 to 15. The final version of the ESDS includes 10 items. The total ESDS ranges from 10 to 51, with higher scores reflecting greater enforced dependency.

Method of Administration

The ESDS was developed as an interview guide on which responses to questions covering the 10 activities are recorded. Verbal descriptions of the levels of functioning were operationally defined and coded for each activity. In order to determine the appropriate location on the scale for a particular patient, the subjects are asked standardized questions related to each concept. Regarding personal competence, subjects are asked if their routines of eating, dressing, walking, traveling, bathing, and toileting are normal in relation to what had been customary prior to illness. If not, they are asked if they use equipment, if they need the help of another person, and how often these changes occur from routine activities. The interviewer continues to probe to determine whether there is a minor change (score as 2) or a major change (score as 4 or higher). If there had been a change within the preceding two weeks, the most recent condition identified by the subjects is recorded.

Questions related to the concept of social competence include activities in three areas: activities in the home, work activities, and social and recreational activities Subjects are asked if their activities have changed in relation to what has been customary prior to illness. One activity is questioned at a time in the interview. The first question in the semistructured guide for each item is general and open-ended. All questions are phrased in simple language for the layperson. Since many subjects are on cancer treatment or at various stages of disease, it is imperative that the questions be brief and simple enough for them to understand, so as to avoid error. Although there is standardization of questioning through the specifications of interview guidelines, further probing questions are often necessary and are provided for clarification of deviations from normal patterns. The questions are constructed on the principle that as many questions as necessary should be asked using the standardized form to determine where a patient scores on a particular item. Recall of activities over the 2 weeks prior to the interview also help to delineate a time frame and refresh memory for some subjects. In addition, subjects are evaluated according to their consciousness patterns regarding awareness of self-identity and location and awareness of situations with reference to time, place, and identity of persons. Disorientation at any time over a 24-hour period, i.e., during the night or from the influence of medications, is also noted.

There are two versions of the ESDS. The final or first version is used when subjects are to be tested only once (see Appendix A). The second version is used when the investigator plans to collect functional data over time (see Appendix B). The second version is to be used with each subsequent wave of data collection.

Following collection of data, the responses are coded according to pre-established coding categories that represent specific competence levels on a Likert-type scale. Responses to the standardized questions for each activity are written in narrative form on the interview guide (see Appendix C for a copy of the coding instructions).

Scoring Procedures

Total score of the ESDS is obtained as the unweighted sum of 10 items with scores ranging from 10 to 51. Higher scores indicate greater enforced dependency. Since the number of scale levels varied from 3 to 6 for the items of the ESDS, the item variances were necessarily unequal, with items having larger variance receiving greater implicit weighting in a simple sum score. When items were standardized and summed (thus giving equal weight to each item), the resulting composite was almost perfectly correlated with the sum of the unstandardized items, so this effect was negligible. The simple raw score sums were therefore used.

The Use of Enforced Social Dependency Scale

The scale was developed to determine the extent to which the patient's dependency on external sources of support has changed during the course of illness. The scale has proven to be sensitive to the patient's changes in levels of dependency over time. The ESDS also can be used to guide the adjustment of clinical interventions according to the changes in the functional status of a patient. Finally, the ESDS can be used to evaluate outcomes of clinical interventions.

The advantages of the ESDS scale are threefold. First, it takes a relatively short time for an interviewer to administer the scale, between 10 and 20 minutes. Second, the scale is constructed as a semistructured interview guide and gives subjects an opportunity to share their perception of what is happening. Third, responses are scored on standardized code dimensions so that findings can be compared across groups of patients and over time (Moinpour, McCorkle, & Saunders, 1992).

The ESDS differs in several respects from other commonly used measures of functional status (e.g., Karnofsky performance status scale and Katz activities of daily living scale). First, the ESDS is a self-report scale and may be used without the necessity of collecting data from medical records or health professionals. Second, other commonly used functional status indexes examine function at a single point in time using a cross sectional approach. These indexes may not be sensitive enough for clinical trials designed to test the effect of an intervention on changes of functional status over time or be able to detect small clinically significant differences in individuals. The ESDS assesses changes in function over time by asking direct question related to changes compared to a previous point in time. Third, the ESDS, in addition to measuring the ability to perform physical activities, also contains a component devoted specifically to measuring the dimension of social competence. Social functioning comprises a component of quality of life measures and has not yet received wide attention as a separate construct in clinical research. When it has, it has been used primarily as an endpoint rather than as a prognostic factor. Sensitively detecting and demonstrating the existence of a relationship among social functioning and survival or other important health care outcomes is necessary in proposing clinical interventions for improving health care (Jepson, Schltz, Lusk & McCorkle, 1997).

Chapter 2

Psychometric Properties of the Enforced Social Dependency Scale

If the reliability and validity of a study's data are unknown or inadequate, little faith can be put in the results obtained and the conclusions drawn from the results. Kerlinger (1986) recognized that concern for reliability comes from the necessity for dependability in measurement and that validity of measurement questions the nature of reality. This chapter presents information about the psychometric properties, including reliability and validity, of the ESDS from a variety of perspectives. Definitions of the psychometric terms used in this chapter are provided first, followed by the information about the psychometric properties of the ESDS from the original studies. Information about the internal reliability, test-retest reliability, validity, responsiveness, and reference values of the ESDS as reported in published studies is also included. In order to enable users to compare results from their own study with the ESDS scores obtained in similar samples, summary data about the psychometric properties and reference values from published studies are provided in a tabular format. Finally, previously unpublished data about the psychometric properties of the ESDS from a pooled group of newly diagnosed cancer patients are presented.

Definition of Psychometric Terms

Reliability

Polit and Hungler (1999) defined the reliability of an instrument as the degree of consistency or dependability with which an instrument measures the attribute it is designed to measure. Reliability is the accuracy or precision of a measuring instrument. Synonyms for reliability include dependability, stability, consistency, predictability, and accuracy. The reliability of a measuring tool can be assessed in several different ways. The aspects that have received major quantitative attention are stability and internal consistency.

1. Stability

The stability of a measure refers to the extent to which the same results can be obtained on repeated administrations of the instrument (Polit & Hungler, 1999). The most common assessment is *test-retest reliability*. Test-retest reliability is the correlation between scores from the same subjects tested at two different times. McCorkle (1987) suggested that documenting stability of responses over short periods of time strengthens an attribution of change in scores to the phenomena of interest over a longer time period. The interval between measurements should not be so short that subjects' recall of items can artificially inflate the reliability coefficient nor so long that one is studying the stability of the characteristic over time rather than the performance of the instrument. Jacobson (1997) therefore recommended that two to four weeks is a suitable interval for most estimations of stability. In addition, test-retest reliability is more useful for measures of enduring characteristics than for changeable states (Jacobson, 1997).

2. Internal consistency

Ideally, scales designed to measure an attribute are composed of a set of items, all of which measure the same critical attribute and nothing else. Indices of homogeneity or internal consistency estimate the extent to which different subparts of an instrument are equivalent in terms of measuring the critical attribute (Polit & Hungler, 1999). Higher internal consistency ensures that the total score on a scale is representative of what the diverse items constituting the scale have in common. Cronbach's alpha is the most common method of measuring internal consistency. Jacobson (1997) suggested that reliability is a matter of degree rather than an all-or-nothing affair. The higher the coefficient, the higher the degree of internal consistency. However, there is no standard for what an acceptable reliability coefficient should be. The judgment depends on the nature of the trait being measured and the stage of development of the instrument. Coefficients of 0.60 to 0.70 may be acceptable for the exploratory use of tools in the early stages of development (Jacobson, 1997). Instruments reliabilities of equal to or greater than 0.70 have been suggested for scales being developed for use in group analyses, whereas scale reliabilities of greater than 0.90 have been suggested for scales used at the individual level (Nunnally & Bernstein, 1994; Polit & Hungler, 1999).

Validity

Validity refers to the degree to which an instrument measures what it is supposed to be measuring (Polit & Hungler, 1999). Establishing validity is more difficult than establishing reliability. Achieving reliability is to a large extent a data-based technical matter. However, Kerlinger (1986) recognized that validity bores into the essence of science itself. It also bores into philosophy. Since validity is concerned with the nature of reality and the nature of the properties being measured, it is heavily philosophical (Kerlinger, 1986). Therefore, researchers' judgments are often involved in the evaluation of the validity of an instrument. Face, content, construct, and criterion validity are discussed in this manual.

1. Face validity

Face validity refers to whether the instrument looks as though it is measuring the appropriate concept (Polit & Hungler, 1999). It is a judgment of what the tool appears to measure, based on a cursory inspection by the layman. Face validity is the public relations aspect of a tool; it provides no evidence of what the tool really measures (Jacobson, 1997). Therefore, an instrument needs to demonstrate more than only face validity as the evidence of validation of the instrument.

2. Content validity

Content validity examines the representativeness or sampling adequacy of the content of a measuring instrument (Kerlinger, 1986; Nunnally & Bernstein, 1994) to the universe of concepts or domains that are intended to measure. Content validity relates to the extent to which one can generalize from a particular collection of items to all possible items in a broader domain of items (Nunnally & Bernstein, 1994). Content validity is usually evaluated by consensual judgments from subject matter experts (Jacobson, 1997; Polit & Hungler, 1999).

3. Criterion-related validity

Criterion-related validity is the correlation between a measure and some outside indicator that provides a direct or superior measure of the attribute under study (Jacobson, 1997; Kerlinger, 1986). One requirement of the criterion-related approach to validation is the availability of a reasonably reliable and valid criterion (gold standard) with which the measures on the target instrument can be compared. Two types of criterion-related validity commonly are distinguished, depending on when the criterion data are collected. *Concurrent validity* refers to the ability of an instrument to distinguish individuals who differ in their present status on some criterion (Polit & Hungler, 1999). Concurrent validity is estimated by simultaneously correlating new instruments with valid and reliable instruments measuring similar or like phenomena. For concurrent validity, data about the measure and indicator are collected at the same time and the relationship is assessed between the two instruments. *Predictive validity* refers to the adequacy of an instrument in differentiating between the performance or behaviors of individuals on some future criterion (Polit & Hungler, 1999). For predictive validity, data on the criterion variable are collected from the same subjects at a future date and the measures of interest are correlated to the future assessment.

4. Construct validity

The focus of construct validity is on the theoretical meanings of measurements. Construct validity links psychometric notions and practices to theoretical notions. Jacobson (1997) recognized that construct validity attempts to measure the underlying attribute of the instrument by assessing whether the measurement of one concept is logically related to that of other concepts. Therefore, construct validity is more concerned with the underlying attribute of the instrument than with the scores that the instrument produces (Polit & Hungler, 1999).

There are several approaches to construct validity. In the *known-groups approach*, groups that are expected to differ on the critical attribute are tested on the instrument. If the scores of groups differ significantly in the expected direction, construct validity is supported. *Convergence validity* refers to evidence that different methods of measuring a construct yield similar results. *Discriminant validity* is supported when a measure of one underlying construct can be differentiated from another construct (Polit & Hungler, 1999). Other methods of construct validation include the technique of correlating items with total scores and factor analysis (Kerlinger, 1986). In using the technique of correlating items with total scores, the total score is assumed to be valid. To the extent that an item measures the same thing as the total score does, to that extent the item is valid. Factor analysis is used to identify and group together different measures of same underlying attribute.

Responsiveness

Responsiveness is the ability of a measure to detect a clinically important treatment effect no matter how small the effect is. This attribute is exceptionally important for instruments that act primarily as an outcome measurement (Stewart & Archbold, 1992).

Reference Values

Reference values can be used as indices of scores to facilitate interpretation of an instrument by enabling researchers to compare results obtained in their samples with the scores of other people with similar sociodemographic and health-related characteristics.

Psychometric Properties of the ESDS: Original Studies

Reliability

At the pilot test stage of development of the ESDS, initial reliability was established on 60 patients with progressive chronic illness. Internal reliability was established for the total ESDS and the three subscales (Benoliel, McCorkle & Young, 1980). Cronbach's alpha internal reliability coefficient for the composite social dependency scale was 0.90; the standardized-item alpha was 0.91. The reliability coefficient for the three subscales of ESDS ranged from 0.78 to 0.82; the standardized-item alphas were from 0.82 to 0.87.

At the revision stage of development of the ESDS, McCorkle and Benoliel (1981) reported reliability coefficients for the total scale by disease groups (alpha = 0.84 for cancer and alpha = 0.80 for heart disease) and one month test-retest correlations of 0.62.

Validity

Determinations and selection of appropriate items of the ESDS were done through subject interviews. Initially, self-care, mobility, and social problems were identified by cancer patients as major concerns in the pilot study by McCorkle in 1976. Subsequently, the preliminary ESDS was tested on 10 cancer patients receiving active treatment in an ambulatory care clinic. By these processes, the ESDS was considered as acceptable to cancer patients, therefore, face validity was established. Content validity of the ESDS was established by the thorough review of a group of experts in the field of cancer nursing (Benoliel, McCorkle & Young, 1980).

At the pilot test stage of the ESDS development, Benoliel, McCorkle, and Young (1980) established that corrected item-total correlations of the total ESDS and the three subscales ranged from 0.40 to 0.83 with mean correlation coefficients from 0.65 to 0.73.

McCorkle and Benoliel (1981) conducted factor analysis to confirm two unique factors for the ESDS: personal and social competence. They also used a known group approach to establish construct validity for the ESDS. Based on the conceptualization of different illness trajectories for individuals newly diagnosed with advanced lung cancer and myocardial infraction (MI), the researchers hypothesized that these two groups of patients would differ regarding the social dependency on outside resources. The pattern of social dependency was similar for patients with lung cancer and myocardial infarction at baseline (mean score for the ESDS for patients with lung cancer at occasion 1 was 25.0 and for patients with myocardial infraction was 26.7). At occasion 2, the mean score remained the same (25.1) for lung cancer patients and decreased significantly for MI patients (mean equaled 22.5). There was a significant occasion main effect

(P<0.001) for social dependency for MI patients. Therefore, McCorkle and Benoliel (1981) concluded that cancer patients had different patterns of deterioration of functional independence from patients with myocardial infarction.

Responsiveness

McCorkle and colleagues (1989) used the ESDS as one outcome measure to evaluate the effectiveness of a home care intervention in adults with advanced lung cancer. They demonstrated a significant effect of home care nursing interventions on forestalling functional decline for advanced lung cancer patients (P=0.02). All patients experienced increased dependency over time, but patients receiving home care remained independent for a longer period than the office care group. The office care group experienced increased dependency about 6 weeks earlier than either the oncology specialized home care or standard home care group.

Psychometric Properties of the ESDS: Review of Literature

A comprehensive review of the literature was conducted to identify published studies, theses, and dissertations that have used the ESDS as an explanatory or clinical outcome measure. Computer searches of published articles from 1981 to June 2002 were conducted using MEDLINE, Cumulative Index for Nursing and Allied Health Literature, PsychoInfo, and Health & Psychosocial Instruments. Three different computer searches were performed using the key words functional dependency and cancer/chronic illness, functional status and cancer/chronic illness, and Enforced Social Dependency Scale. In addition, a hand search of the articles identified through the computer searches was conducted to identify additional published articles. Thirty-three articles were identified as appropriate for this discussion. Among these studies, six were conducted before the final revision of the ESDS (McCorkle, Benoliel, Donaldson, Georgiadou, Moinpour& Goodell, 1989), and therefore, scales containing a variety of numbers of items (12, 14, and 17) have been used in these studies. Thereafter, the 10 item ESDS became the norm. The final section of this manual presents an annotated bibliography of the published studies and reports information regarding the purpose, design, sample, measures, and primary findings. In this section, reliability, validity, responsiveness, and reference scores of the ESDS from the published studies are discussed.

Reliability

The reliability of an instrument is not a self-contained property of an instrument but rather of an instrument when it is administered to a certain sample under certain conditions (Jacobson, 1997; Polit & Hungler, 1999). Jacobson (1997) recommended that for all types of reliability, prospective users must ascertain the characteristics of the group on or for whom the tool was developed. The more similar the original group to the user's target group, the more likely that the tool will perform reliably for the new study. Polit and Hungler (1999) suggested that researchers should compute estimates of reliability whenever data are collected for a scientific investigation.

The ESDS has been used in a variety of patient populations and settings and information related to internal consistency reliability of this instrument is available from 30 different studies.

These studies are listed in Table 5 in chronological order followed by alphabetical order of the first author. Some of the studies are repeated in the table because the researchers reported more than one reliability coefficient. Reported Cronbach's alphas have ranged from 0.52 (Cochrane, 1992) to 0.96 (Barsevick, Pasacreta & Orsi, 1995). For studies with various types of cancer, reported Cronbach's alphas ranged from 0.73 (Young Graham & Longman, 1987) to 0.96 (Barsevick, Pasacreta & Orsi, 1995). For studies that were conducted among patients with myocardial infraction, the reported Cronbach's alphas were from 0.52 (Cochrane, 1992) to 0.89 (Cowan, Graham & Cochrane, 1992). Most of the studies that used ESDS reported Cronbach's alpha levels greater than 0.80.

Table 5. Internal Consistency Reliability for Studies Using the ESDS Scale

First Investigator (Year)	N	Sample		Cronbach Alpha Reliability
McCorkle (1981)	61	Lung Cancer	one month post-diagnosed	0.80
			two months post-diagnosed	0.88
	52	Myocardial infarction	one month post-diagnosed	0.77
			two months post-diagnosed	0.82
Young (1983)	23	Malignant melanoma		NR
Fink (1985)		Amyotrophic lateral sclerosis		0.92
Donaldson (1986)	56	Lung Cancer	one month post-diagnosed	0.80
			two months post-diagnosed	0.88
	65	Myocardial infarction	one month post-diagnosed	0.77
			two months post-diagnosed	0.82
Kukull (1986)	53	Inoperable lung cancer		0.82
Degner (1987)	29	Various types of terminal cancer	< 48hrs of admission	0.79
			7 days after 1st test	0.82
Young Graham (1987)	60	Malignant melanoma		0.73
McCorkle (1989)	166	Lung cancer		0.79
Edwards (1990)	117	Patients receiving selective elective abdominal surgeries		0.79

(Table continued)

Table 5. Internal Consistency Reliability for Studies Using the ESDS Scale

First Investigator (Year)	N	Sample		Cronbach Alpha Reliability
Naylor (1990)	40	Elderly patients primary with cardiac medical and surgical problems		NR
Willard (1990)	38	Total knee and total hip replacement procedures		NR
Cochrane (1992)	16	Myocardial infraction		0.52
Cowan (1992)	57	malignant melanoma and myocardial infraction		0.89
DesRosier (1992)	9	Wives of patients with multiple sclerosis		NA
Long (1992)	361	Multiple sclerosis		0.90*
Taylor (1992)	74	Various recurrent cancer		0.85
O'Hare (1993)	63	Black patients with various solid tumors		0.83
Sarna (1993)	28	Lung cancer		NR
Taylor (1993)	74	Various recurrent cancer		0.85
Yost (1993)	130	Various solid tumors		NR
McCorkle (1994)	60	Various solid tumors	Discharge	0.81
			Three months post-discharge	0.90
Sarna (1994)	60	Lung cancer		0.79
Weinert (1994)	604	Multiple sclerosis		0.92
Barsevick (1995)	66	Colorectal cancer post-surgery		0.96
Robinson (1995)	90	Chronically ill adults (DM, COPD, essential hypertension)		0.89
Jepson (1997)	141	Solid tumors	Personal competence	0.78
			Social competence	0.69
Pasacreta (1997)	79	women with breast cancer 3 to 7 months post-diagnosis		0.77
York (1997)	96	Childbearing women with diabetes or hypertension		0.65
McCorkle (1998)	37	Newly diagnosed older terminal cancer patients	Personal competence	0.79
			Social competence	0.72

(Table continued)

Table 5. Internal Consistency Reliability for Studies Using the ESDS Scale

First Investigator (Year)	N	Sample		Cronbach Alpha Reliability
Naylor (1999a)	363	Elderly patients with various medical and surgical problems		NR
Naylor (1999b)	202	Elderly patients with various medical and surgical problems		NR
Nuamah	375	Newly diagnosed elderly postsurgical cancer patients	Baseline	0.76
			3 months follow-up	0.82
Ring (1999)	22	Elderly patients with an atrophic, ununited fracture of the humeral diaphysis		NR
McCorkle (2000)	375	Newly diagnosed post-surgical elderly cancer patients		NR

* Coefficient alpha for the personal competence subscale

NR: Not reported

NA: Not applicable

Among the identified thirty-three studies, 15 were cross-sectional design, therefore, test-retest reliability didn't apply to these studies (Table 6). However, for the other 18 studies, only three studies explicitly revealed test-retest reliability in the articles and correlation coefficients of those studies ranged from 0.36 to 0.62. Test-retest reliability was measured at one-month intervals in two of these three studies. In the other study, ESDS was repeatedly measured within one week of hospital admission, one to two weeks after discharge, and 8 to 10 weeks after discharge.

Table 6. Test-Retest Reliability for Studies Using the ESDS Scale

First Investigator (Year)	N	Sample	Test-Retest Reliability
McCorkle (1981)	61	Lung cancer	0.62
	52	Myocardial infraction	
Young (1983)	23	Malignant melanoma	NA
Fink (1985)		Amyotrophic lateral sclerosis	NA
Donaldson(1986)	56	Lung cancer	0.48
	65	Myocardial Infraction	0.54
Kukull (1986)	53	Inoperable lung cancer	0.79

(Table continued)

Table 6. Test-Retest Reliability for Studies Using the ESDS Scale

First Investigator (Year)	N	Sample	Test-Retest Reliability
Degner (1987)	29	Various types of terminal cancer	NR
Young Graham (1987)	60	Malignant melanoma	NA
McCorkle (1989)	166	Lung cancer	0.79
Edwards (1990)	117	Patients receiving selective elective abdominal surgeries	NR
Naylor (1990)	40	Elderly patients primary with cardiac medical and surgical problems	NA
Willard (1990)	38	Total knee and total hip replacement procedures	NR
Cochrane (1992)	16	Myocardial infraction	0.36~0.44
Cowan (1992)	57	30 malignant melanoma and 27 myocardial infraction	NA
DesRosier (1992)	9	Wives of patients with multiple sclerosis	NA
Long (1992)	361	Multiple sclerosis	NA
Taylor (1992)	74	Various recurrent cancer	NA
Sarna (1993)	28	Lung cancer	NR
O'Hare (1993)	63	Black patients with various solid tumors	0.90
Taylor (1993)	74	Various recurrent cancer	NA
Yost (1993)	130	Various solid tumors	0.88
McCorkle (1994)	60	Various solid tumors	0.90
Sarna (1994)	60	Lung cancer	NR
Weinert (1994)	604	Multiple sclerosis	NA
Barsevick (1995)	66	Colorectal cancer post-surgery	NA
Robinson (1995)	90	Chronically ill adults (DM, COPD, essential hypertension)	NA
Jepson (1997)	141	Solid tumors	0.72
Pasacreta (1997)	79	women with breast cancer 3 to 7 months post-diagnosis	NA
York (1997)	96	Childbearing women with diabetes or hypertension	NR
McCorkle (1998)	37	Newly diagnosed older terminal cancer patients	0.73
Naylor (1999a)	363	Elderly patients with various medical and surgical problems	NR
Naylor (1999b)	202	Elderly patients with various medical and surgical problems	NR

(Table continued)

Table 6. Test-Retest Reliability for Studies Using the ESDS Scale

First Investigator (Year)	N	Sample	Test-Retest Reliability
Nuamah (1999)	375	Newly diagnosed post-surgical elderly cancer patients	Nr
Ring (1999)	22	Elderly patients with an atrophic, ununited fracture of the humeral diaphysis	NR
McCorkle (2000)	375	Newly diagnosed post-surgical elderly cancer patients	NR

NR: Not reported

NA: Not applicable

Validity

Evidence of both concurrent and predictive validity of the ESDS was observed in various published studies. Table 7 presents the information about the concurrent correlations of the ESDS and the scores on other instruments. All of the correlations of instruments used in the studies included in Table 7 and the ESDS were significant at least at $p<0.05$ level. Concurrent validity of the ESDS was commonly established by correlating the ESDS with other measurements of functional status (Functional Status Questionnaire Scale and Functional Status Instrument) and quality of life (Quality of Life Index). Considering the fact that: 1) functional status is one of the major components of quality of life, and 2) higher scores of the Quality of Life Index indicate better quality of life, the ESDS was strongly inversely related to the Quality of Life Index, with a range from –0.40 to –0.70 in these identified published studies. Specifically, Willard (1990) used the ESDS as the gold standard measure to establish concurrent validity of Functional Status Instrument. Willard (1990) administered the ESDS and Functional Status Instrument to 38 patients receiving total knee or total hip replacement surgeries. In the pre-operative assessment, Willard (1990) demonstrated nearly perfect correlation (r=0.98) between the ESDS and the Functional Status Instrument. In the post-operative assessment, the correlations between the ESDS and the Functional Status Instrument were 0.59 and 0.79 on post-operative day one and 10, respectively. The high correlations between the ESDS and the Functional Status Instrument lend evidence that the Functional Status Instrument is measuring functional status. In the same study, Willard (1990) also showed that the correlation between the scores on the ESDS and acuity levels of subjects was strong, positive, and significant (r=0.74, P=0.01).

Table 7. Concurrent Validity Between the ESDS and Other Instruments

First Investigator (Year)	N	Sample	Instrument	Correlation (P value)
Degner (1987)	29	Terminal cancer	QL-Index (assessed by nurses)	-0.49 (P=0.01)
Willard (1990)	38	Total knee and total hip replacement procedures	Functional Status Instrument pre-operative	0.98 (P<0.008)
			Functional Status Instrument post-operative day one	0.59 (P=0.081)
			Functional Status Instrument post-operative day 10	0.79 (P=0.009)
Cowan (1992)	30	Malignant melanoma	Functional Status Questionnaire Scale	-0.39 (NR)
			Quality of Life Index	-0.70 (P<0.001)
	57	Chronic illness	Quality of Life Index	-0.40 (P<0.01)

A number of studies supported the predictive validity of the ESDS. Enforced social dependency was a significant predictor of survival in patients with various cancers (Jepson, Schultz, Lusk & McCorkle, 1997; McCorkle, Hughes, Robinson, Levine & Nuamah, 1998). Jepson and colleagues (1997) demonstrated that, among a variety of measures, only the ESDS (including both personal and social dependency subscales) were found to contribute significantly to the prediction of survival time. McCorkle and colleagues (1998) reported remarkable differences in the enforced social dependency between patients dying within 6 months of their initial surgery and those who died after that period of time. Intense levels of enforced social dependency were reported by the patients in the early-dying group from the 3-month follow-up and afterwards. Willard (1990) used the ESDS to predict length of post-operative hospitalization for patients receiving total knee or total hip replacement procedures. Willard (1990) demonstrated that the correlation between the scores on the ESDS and length of stay was strong, positive, and significant (r=0.75, P=0.016). Higher scores on ESDS predicted longer length of stay in this group of patients.

In addition, the ESDS was commonly correlated with measurements of quality of life (Life Change Scale, and Purpose in Life), Symptom Distress Scale (SDS), and Psychosocial Adjustment to Illness Scale (Table 8) in the published studies. As expected, enforced social dependency was positively associated with symptom distress in all of the studies (correlation coefficients of the ESDS with the SDS as between 0.31 to 0.66). Furthermore, findings from reported studies demonstrated that enforced social dependency negatively impacted on psychosocial adjustment to illness, quality of life, purpose in life, life change, and sense of coherence. In other words, as someone becomes less independence (higher enforced social dependency), scores on quality of life measures decrease.

Table 8. Correlations Between the ESDS and Other Instruments

First Investigator (Year)	N	Sample	Instrument	Correlation (*p* value)
Fink (1985)		ALS patients	Sickness Impact Profile	0.89
Young (1983)	23	Malignant melanoma	Quality of life (developed by investigators)	-0.34 (p=0.01)
			Symptom Distress Scale	0.54 (p=0.001)
			MacElveen Behavior-Morale Scale	-0.29 (p=0.027)
Young Graham (1987)	60	Malignant melanoma	Quality of life (developed by investigators)	-0.28 (p=0.016)
			Symptom Distress Scale	0.31 (p=0.008)
			Behavior-Morale Scale	-0.34 (p=0.004)
			Life Change Scale (developed by investigators)	0.39 (p=0.001)
			Direction of Life Change (developed by investigators)	0.42 (p=0.000)
Edwards (1990)	117	Selective elective abdominal surgeries	Health Perception Questionnaire 26-item scale	0.23 (p<0.01)
			Perceived Stress 10-item Scale	-0.19 (p<0.05)
Cowan (1992)	30	Malignant melanoma	Revised Psychosocial Adjustment to Illness Scale	0.35 (p<0.01)
			Symptom Distress Scale	0.44 (p<0.01)
	27	Myocardial infraction	Symptom Distress Scale	0.66 (p<0.01)
	57	Chronic illness	Symptom Distress Scale	0.54 (p<0.001)
			Sense of Coherence Scale	-0.28 (p<0.001)
Taylor (1992)	74	Recurrent cancer	Purpose in Life	-0.28 (p<0.01)
			Psychosocial Adjustment to Illness Scale	0.50 (p<0.001)
			Symptom Distress Scale	0.47 (p<0.001)

(Table continued)

Table 8. Correlations Between the ESDS and Other Instruments

First Investigator (Year)	N	Sample	Instrument	Correlation (*p* value)
Cochrane (1992)	16	Myocardial infraction	Coherence Scale (within 1 week of admission)	-0.59 (p<0.01)
Taylor (1993)	74	Recurrent cancer	Purpose in Life	-0.28 (p<0.01)
			Psychosocial Adjustment to Illness Scale	0.50 (p<0.001)
			Symptom Distress Scale	0.47 (p<0.001)
Pasacreta (1997)	79	women with breast cancer	CES-D	0.48 (p<0.001)
			Symptom Distress Scale	0.53 (NR)

NR: Not reported

Responsiveness

McCorkle and colleagues (1994) addressed the responsiveness of the ESDS in a study evaluating the impact of home care services on measures of symptom distress, mental health, enforced social dependency, and health perceptions of cancer patients following an acute care hospital stay. This study demonstrated that patients who received home care had significant improvements in enforced social dependency over time as compared with no home care group. McCorkle and colleagues (1994) concluded that home care had a beneficial effect on patients' psychosocial outcomes.

Reference Values

Reference values are provided in this manual to enable researchers to compare results obtained in their samples with the scores of other people with similar sociodemographic and health-related characteristics. Table 9 provides information for the samples (and subsamples) of patients reported in the literature: including the mean ESDS scores, standard deviations and the range of scores reported in each article.

Focused on studies utilizing 10 items ESDS, reported mean scores of the ESDS ranged from 16.9 for patients with acute myocardial infraction measured at 8-10 weeks after hospitalization (Cochrane, 1992) to 33.6 for newly diagnosed older terminal cancer patients measured at baseline (McCorkle, Hughes, Robinson & Nuamah, 1998). For studies with various types of cancer, reported mean scores of the ESDS ranged from 17.3 (Pasacreta, 1997) to 33.6 (McCorkle, Hughes, Robinson & Nuamah, 1998). The majority of studies used the ESDS reported mean scores from 20 to 25.

Table 9. Mean, Standard Deviation, and Range of ESDS Scores for Studies

First Investigator (Year)	N	Sample		No of Items	Mean (Range)	SD
McCorkle (1981)	61	Lung cancer	one month	14	25.0 (14~55)	6.2
			two month		25.1 (14~57)	7.8
	52	Myocardial infarction	one month	14	26.7 (14~58)	5.6
			two month		22.5 (14~54)	5.8
Young (1983)	23	Malignant melanoma		12	NR	NR
Donaldson (1986)	56	Lung cancer	one month	14	25.0	8.0
			two month	14	25.0	8.0
	65	Myocardial infarction	one month	14	25.3	4.9
			two month	14	22.1	5.1
Kukull (1986)	53	Inoperable lung cancer	one month	14	25.1	6.2
			two month	14	25.6	7.8
Degner (1987)	29	Various types of terminal cancer	< 48hrs of admission	17	37.2	NR
			7 days after 1st test		43.3	NR
Young Graham (1987)	60	Malignant melanoma		12	NR	NR

(Table continued)

Table 9. Mean, Standard Deviation, and Range of ESDS Scores for Studies

First Investigator (Year)	N	Sample		No of Items	Mean (Range)	SD
McCorkle (1989)	42	Lung cancer oncology home care	Occasion one		23.7	8.0
	34		Occasion two		23.9	7.7
	32		Occasion three		25.4	9.2
	24		Occasion four		23.8	7.8
	22		Occasion five		24.2	7.8
	38	Lung cancer standard home care	Occasion one		23.2	7.3
	37		Occasion two		24.2	9.1
	32		Occasion three		23.6	8.5
	27		Occasion four		25.7	9.6
	19		Occasion five		24.3	8.0
	43	Lung cancer office care	Occasion one		22.4	6.2
	33		Occasion two		23.7	6.5
	27		Occasion three		26.3	8.4
	24		Occasion four		25.4	9.7
	19		Occasion five		26.0	11.0
Edwards (1990)	117	Patients received selective elective abdominal surgeries	10^{th} to 12^{th} day post-surgery	10*	30.3 (20~42)	NR
			3 weeks post-surgery		35.6 (26~42)	NR
			3 weeks post-surgery		39.7 (33~42)	NR
Naylor (1990)	Elderly patients primary with cardiac medical/ surgical problems					
	20	Experimental group	personal competence	6	10.7	4.0
			social competence	4	5.4	1.7
	20	Control group	personal competence	6	15.7	6.13
			social competence	4	5.8	2.1
Willard (1990)	38	Total knee and total hip replacement procedures		10	NR	NR

(Table continued)

Table 9. Mean, Standard Deviation, and Range of ESDS Scores for Studies

First Investigator (Year)	N	Sample		No of Items	Mean (Range)	SD
Cochrane (1992)	16	Acute Myocardial infraction	within 1 week of admission	10	31.8	3.1
			1-2 weeks after discharge		23.7	4.2
			8-10 weeks after discharge		16.9	2.9
			Overall		24.3 (11~40)	7.0
Cowan (1992)	30	Malignant melanoma		10	NR	NR
	27	Myocardial infraction		10	NR	NR
DesRosier (1992)	9	Wives of patients with multiple sclerosis		6**	21.1 (6~27)	9
Long (1992)	361	Multiple sclerosis		6**	12.3	6.6
Taylor (1992)	74	Various recurrent cancer		10	22.0 (11~38)	6.9
O'Hare (1993)	63	Black patients with solid tumors		10	29.3	8.5
Sarna (1993)	28	Lung cancer following radiation therapy	2 months after diagnosis	10	22.7 (12~46)	NR
			3 1/2 months after diagnosis		20.7 (10~36)	NR
			5 months after diagnosis		20.9 (11~29)	NR
			6 1/2 months after diagnosis		20.1 (11~30)	NR
			8 months after diagnosis		20.0 (11~28)	NR
Taylor (1993)	74	Various recurrent cancer		10	22.0 (11~38)	6.9
Yost (1993)	130	Various solid tumors		10	NR	NR
McCorkle (1994)	60	Solid tumors home care	Discharge	10	30.8	7.0
			Three months post-discharge		24.6	9.6
		Solid tumors no home care	Discharge		24.5	10.1
			Three months post-discharge		27.3	10.7

(Table continued)

Table 9. Mean, Standard Deviation, and Range of ESDS Scores for Studies

First Investigator (Year)	N	Sample		No of Items	Mean (Range)	SD
Sarna (1994)	60	Lung cancer	2 months after diagnosis	10	22.0 (11~41)	7.0
			3 1/2 months after diagnosis		23.0 (10~40)	7.0
			5 months after diagnosis		24.0 (11~44)	7.0
			6 1/2 months after diagnosis		24.0 (11~40)	8.0
			8 months after diagnosis		25.0 (13~41)	7.0
Weinert (1994)	604	Multiple sclerosis		6	12.8	6.5
Barsevick (1995)	66	Colorectal cancer post-surgery		10	NR	NR
Robinson (1995)	90	Chronically ill adults (DM, COPD, essential hypertension)		10	17.0 (10~37)	6.0
Jepson (1997)	141	solid tumors	personal competence	6	18.1 (6~33)	6.3
			social competence	4	9.1 (3~12)	2.4
Pasacreta (1997)	79	women with breast cancer 3 to 7 months post-diagnosis		10	17.2 (10~27)	4.5
York (1997)	96	Childbearing women with diabetes or hypertension		10	NR	NR
McCorkle (1998)	37	Newly diagnosed older terminal cancer patients	Baseline	10	33.6	5.7
			3 months		26.1	8.2
			6 months		25.0	11.4
Naylor (1999a)	363	Elderly persons with medical and surgical problems	Intervention Group (IG)	10	22.4	8.1
			control group (CG)		22.6	8.4

(Table continued)

Table 9. Mean, Standard Deviation, and Range of ESDS Scores for Studies

First Investigator (Year)	N	Sample			No of Items	Mean (Range)	SD
Naylor (1999b)	202	Elderly persons with medical and surgical problems	IG	T1	10	17.5-25.5	NR
				T2		26.2-26.5	
				T3		28.8-24.8	
				T4		26.4-23.6	
				T5		14.3-23.2	
			CG	T1		16.4-24.9	NR
				T2		26.9-27.0	
				T3		21.9-25.4	
				T4		16.8-23.9	
				T5		15.1-23.1	
Nuaman (1999)	375	Newly diagnosed elderly postsurgical cancer patients	Baseline		10	34.4	5.6
			3 months follow-up			20.8	8.1
Ring (1999)	22	Elderly patients with an atrophic, ununited fracture of the humeral diaphysis	Preoperation		10 (possible range of score 0~100)	39 (25~48)	NR
			Postoperation most recent follow-up			9 (0~36)	NR
McCorkle (2000)	375	Newly diagnosed post-surgical elderly cancer patients	IG	Baseline	10	34.6	5.8
				3 months		20.4	7.8
				6 months		18.9	8.0
			CG	Baseline		34.1	5.5
				3 months		19.2	7.2
				6 months		16.9	6.9

* Higher scores indicate higher independent level of functional status

** Scores for personal competence subscale

NR: Not reported

Psychometric Properties of the ESDS: Newly Diagnosed Cancer Patients

In the following sections, previously unpublished data about the psychometric properties of the ESDS when used with newly diagnosed cancer patients are provided. The primary goal of this summary data is to present item and scale level data that demonstrates how the ESDS performs, from a psychometric perspective, when it was used with cancer patients who were diagnosed within the first 100 days. The secondary goal of this presentation is to provide data to enable users of the ESDS to compare results obtained in their samples with results obtained by the scale developers. Data from four data sets were combined for the psychometric analyses. The data come from four research studies funded by the National Institute of Health from 1983 to 1997. Patients who were within 100 days of diagnosis of their cancer were included in this sample. A brief overview of the four studies is presented first, followed by descriptions of the demographic characteristics of subjects. Item frequency distributions and item means of the ESDS, and item-total correlations, reliabilities and mean scores of the ESDS are provided by study and by cancer site. Comparisons of group means of the ESDS scores on demographic and clinical characteristics will be presented. Finally, changes of scores of the ESDS over time by study, cancer site, and selected demographic and clinical characteristics are discussed and presented by tables and figures.

Overview of the Four Studies

The first study, "Evaluation of Cancer Management", Grant Number NU01001, 1/1/83-6/30/86, was designed as a randomized clinical trial to compare the psychosocial responses and the coping effectiveness of lung cancer patients. Study subjects were randomly assigned to one of three treatment groups (routine office care, standard home care, or specialized home care with advanced practice oncology nurses) over a six-month period. A total of 80 males and 50 females were included in this study. The sample was composed of patients with stage II lung cancer or greater at diagnoses. The majority of subjects had advanced disease (stage III or greater) and radiation therapy was their primary cancer treatment.

The second study, "Evaluation of Home Care for Cancer Patients", Grant Number NR01914, 9/28/87-7/31/91, was in response to an RFA from the National Cancer Institute and was designed to describe the impact of home care services on patients with cancer discharged from the hospital with complex nursing care requirements and a family caregiver. The total sample consisted of both newly diagnosed patients and patients living with cancer. The subsample reported here were all newly diagnosed with multiple sites, including colorectal, lung, head and neck, breast, ovarian, and prostate. Thirty-eight males and 47 females were included in this subsample to be analyzed in this section. These patients were treated with surgery and received adjuvant therapy after they recovered from their surgery and during the study period.

The third study, "Factors Affecting Recovery from Colorectal Cancer Surgery", Grant Number NR02324, 9/1/89-8/31/94, was designed to examine the relationships among psychological distress, symptom distress, expectations about outcome, functional dependency, and immune response over time. The sample consisted of 57 males and 35 females. Patients in this study received surgery as their primary treatment and required little or no additional

treatment over the course of the study.

The fourth study, “Nursing’s Impact on Quality of Life Outcomes in Elders”, Grant Number NR 03229, 9/30/92-8/31/97, was designed to test the effects of a standardized nursing intervention protocol (SNIP) on quality of life and survival outcomes for post surgery older cancer patients over time. The sample included 180 males and 202 females. Patients in this study were all over age 60 years. All were newly diagnosed and the majority of these subjects had early staged cancers, including breast, prostate, colorectal, lung, and head and neck. These patients were discharged with complex problems requiring ongoing nursing monitoring. Many patients receiving adjuvant cancer therapies during the study period.

In the following discussion and tables, the first study is labeled as “ Lung Cancer”, the second study is labeled “ Homecare Multiple Sites”, the third study is labeled “ Colorectal Cancer”, and the fourth study is labeled “ Elders Multiple Sites”. The combined data are listed in the right hand column under the heading “ Total”.

Description of Demographic Data for the Cancer Patients

Demographic data of the participants for each of the four studies separately and overall are provided in Table 10. Within each study, there is diversity among the patients in gender, race (except for the Lung Cancer study), marital status, education (except for the Colorectal Cancer study), religion, employment status, age, and stage of cancer. In summary, among the total of 705 subjects, the majority of them were white, married, with greater or equal to 12 years education, and older than 60 years old. Two studies were restricted to single cancer sites (lung and colorectal cancer). Except for the Elders Multiple Sites study, the patients were recruited predominantly with late stage cancers.

Table 10. Summary of Demographics for the Cancer Patients
N=705

Study Variables	Elders Multiple Site	Homecare Multiple Site	Colorectal Cancer	Lung Cancer	Total
Gender					
Male	180 (47.1%)	38 (44.7%)	57 (62.0%)	80 (61.5%)	325 (47.2%)
Female	202 (52.9%)	47 (55.3%)	35 (38.0%)	50 (38.5%)	364 (52.8%)
Missing = 16					
Race					
White	279 (73.0%)	62 (72.9%)	82 (89.1%)	143 (100%)	566 (80.6%)
Black	95 (24.9%)	21 (24.7%)	9 (9.8%)	-----	125 (17.8%)
Asian	5 (1.3%)	1 (1.2%)	-----	-----	6 (0.9%)
Hispanic	2 (0.5%)	1 (1.2%)	-----	-----	3 (0.4%)
Other	1 (0.3%)	-----	1 (1.1%)	-----	2 (0.3%)
Missing = 3					
Marital Status					
Single	21 (5.5%)	13 (15.3%)	56 (60.9%)	10 (7.1%)	100 (14.3%)
Married	249 (65.2%)	54 (63.5%)	31 (33.7%)	106 (75.2%)	440 (62.9%)
Divorced	34 (8.9%)	18 (21.2%)	5 (5.4%)	25 (17.7%)	82 (11.7%)
Widowed	78 (20.4%)	-----	-----	-----	78 (11.1%)
Missing = 5					
Education					
< 12 years	91 (23.8%)	33 (38.8%)	94 (100%)	48 (33.6%)	266 (37.7%)
12 years	127 (33.2%)	28 (32.9%)	-----	42 (29.4%)	197 (27.9%)
>12 years	165 (43.1%)	24 (28.2%)	-----	53 (37.1%)	242 (34.3%)
Mean	13.4	12.0	4.1	12.2	11.8
SD	5.7	3.4	1.6	3.0	5.5
Missing = 0					
Religion					
None	20 (5.2%)	1 (1.2%)	37 (40.2%)	33 (23.6%)	91 (13.0%)
Protestant	173 (45.3%)	44 (51.8%)	36 (39.1%)	69 (49.3%)	322 (46.1%)
Catholic	130 (34.0%)	29 (34.1%)	10 (10.9%)	28 (20.0%)	197 (28.2%)
Jewish	51 (13.4%)	9 (10.6%)	7 (7.6%)	4 (2.9%)	71 (10.2%)
Other	8 (2.2%)	2 (2.4%)	2 (2.2%)	6 (4.3%)	18 (2.6%)
Missing = 6					

Table 10. Summary of Demographics for the Cancer Patients
N=705

Study Variables	Elders Multiple Site	Homecare Multiple Site	Colorectal Cancer	Lung Cancer	Total
Employment					
Full time	74 (19.4%)	18 (21.2%)	5 (5.5%)	19 (13.5%)	116 (16.6%)
Part time	22 (5.8%)	5 (5.9%)	14 (15.4%)	12 (8.5%)	53 (7.6%)
Unemployed	6 (1.6%)	1 (1.2%)	14 (15.4%)	42 (30.0%)	63 (9.0%)
Disabled	14 (3.7%)	14 (16.5%)	8 (8.8%)	52 (36.9%)	88 (12.6%)
Retired	226 (59.2%)	37 (43.5%)	24 (26.4%)	5 (3.6%)	292 (41.8%)
Homemaker	40 (10.5%)	10 (11.8%)	10 (11.0%)	11 (7.8%)	71 (10.2%)
Student	-----	-----	6 (6.6%)	-----	6 (0.9%)
Other	-----	-----	10 (11.0%)	-----	10 (1.4%)
Missing = 6					
Age					
<65	122 (31.9%)	46 (54.1%)	48 (51.1%)	79 (55.2%)	295 (41.8%)
65-75	209 (54.6%)	29 (34.1%)	38 (40.4%)	50 (35.0%)	326 (46.2%)
>75	52 (13.6%)	10 (11.8%)	8 (8.5%)	14 (9.8%)	84 (11.9%)
Mean	68.7	60.8	62.0	63.0	65.7
SD	6.0	13.5	12.5	10.2	9.7
Missing = 0					
Cancer Site					
Breast/Gyn	97 (25.4%)	13 (15.3%)	-----	-----	110 (15.7%)
Colorectal	71 (18.6%)	34 (40.0%)	92 (100%)	-----	197 (28.1%)
Head/Neck	30 (7.9%)	13 (15.3%)	-----	-----	43 (6.1%)
Lung	68 (17.8%)	19 (22.4%)	-----	142 (100%)	229 (32.7%)
Prostate	84 (22.0%)	5 (5.9%)	-----	-----	89 (12.7%)
Other	32 (8.4%)	1 (1.2%)	-----	-----	33 (4.7%)
Missing = 4					
Stage of Cancer					
Early	254 (67.9%)	20 (29.9%)	-----	15 (10.5%)	289 (49.5%)
Late	120 (32.1%)	47 (70.2%)	-----	128 (89.5%)	295 (50.5%)
Missing = 121					

Summary of Item Frequency Distributions by Study Site

The frequency distributions for each item of the ESDS are provided in Table 11, including the number and percentage of study participants who chose each option. From this analysis, results show that for the total sample and within each study, except for very few items, all options were selected by at least some of the study participants. This evidence suggests that the content of the 10 items and response options are relevant to newly diagnosed cancer patients. The analysis also shows that response distributions were unimodal. Except for communication (item 10), there are no obvious problems with either floor or ceiling effects, which would be evident only if more than 70% of the respondents chose a single extreme option (either the highest or lowest). From this analysis, evidence is shown that the highest functional competence of the study subjects was in communication, followed by toileting and bathing. On the other hand, the newly diagnosed cancer patients were most socially dependent in traveling, work activities, activities in the home, and recreational and social activities. Such results confirmed the observations from the pilot study of the ESDS that cancer limits the patient's social competence before it affects the patient's ability to perform self-care.

Table 11. Item Frequency Distributions by Study Site: Time 1
N= 695

Study Variables	Elders Multiple Site	Homecare Multiple Site	Colorectal Cancer	Lung Cancer	Total
Item 1—Eating/Feeding					
1	47 (12.4%)	10 (12.2%)	10 (10.8%)	25 (17.9%)	92 (15.7%)
2	82 (21.6%)	26 (31.7%)	56 (60.2%)	77 (55.0%)	241 (34.7%)
3	13 (3.4%)	6 (7.3%)	10 (10.8%)	1 (0.7%)	30 (4.3%)
4	201 (52.9%)	24 (29.3%)	16 (17.2%)	37 (26.4%)	278 (40.0%)
5	2 (0.5%)	-----	-----	-----	2 (0.3%)
6	35 (9.2%)	16 (19.5%)	1 (1.1%)	-----	52 (7.5%)
Item 2-- Dressing					
1	34 (8.9%)	24 (29.3%)	28 (30.1%)	50 (35.7%)	136 (19.6%)
2	33 (8.7%)	17 (20.7%)	20 (21.5%)	48 (34.3%)	118 (17.0%)
3	98 (25.8%)	10 (12.2%)	29 (31.2%)	6 (4.3%)	143 (20.6%)
4	53 (13.9%)	11 (13.4%)	4 (4.3%)	10 (7.1%)	78 (11.2%)
5	2 (0.5%)	1 (1.2%)	-----	-----	3 (0.4%)
6	160 (42.1%)	19 (23.2%)	12 (12.9%)	26 (18.6%)	217 (31.2%)

(Table continued)

Table 11. Item Frequency Distributions by Study Site: Time 1
N= 695

Study Variables	Elders Multiple Site	Homecare Multiple Site	Colorectal Cancer	Lung Cancer	Total
Item 3-- Walking					
1	20 (5.3%)	10 (12.2%)	11 (11.8%)	9 (6.4%)	50 (7.2%)
2	136 (35.8%)	35 (42.7%)	55 (59.1%)	78 (55.7%)	304 (43.7%)
3	15 (3.9%)	4 (4.9%)	12 (12.9%)	13 (9.3%)	44 (6.3%)
4	192 (50.5%)	29 (35.4%)	14 (15.1%)	30 (21.4%)	265 (38.1%)
5	16 (4.2%)	3 (3.7%)	-----	7 (5.0%)	26 (3.7%)
6	1 (0.3%)	1 (1.2%)	1 (1.1%)	3 (2.1%)	6 (0.9%)
Item 4—Traveling					
1	4 (1.1%)	9 (11.0%)	13 (14.0%)	26 (11.8%)	52 (7.5%)
2	9 (2.4%)	7 (8.5%)	11 (11.8%)	29 (20.7%)	56 (8.1%)
3	7 (1.8%)	4 (4.9%)	1 (1.1%)	16 (11.4%)	28 (4.0%)
4	45 (11.8%)	22 (26.8%)	29 (31.2%)	29 (20.7%)	125 (18.0%)
5	89 (23.4%)	32 (39.0%)	37 (39.8%)	31 (22.1%)	189 (27.2%)
6	226 (59.5%)	8 (9.8%)	2 (2.2%)	9 (6.4%)	245 (35.3%)
Item 5-- Bathing					
1	25 (6.6%)	19 (23.2%)	32 (34.4%)	44 (31.4%)	120 (17.3%)
2	62 (16.3%)	25 (30.5%)	29 (31.2%)	35 (25.0%)	151 (21.7%)
3	11 (2.9%)	3 (3.7%)	13 (14.0%)	24 (17.1%)	51 (7.3%)
4	258 (67.9%)	33 (40.2%)	17 (18.3%)	26 (18.6%)	334 (48.1%)
5	21 (5.5%)	1 (1.2%)	2 (2.2%)	9 (6.4%)	33 (4.7%)
6	3 (0.8%)	1 (1.2%)	-----	2 (1.4%)	6 (0.9%)
Item 6-- Toileting					
1	101 (26.6%)	25 (30.5%)	17 (18.3%)	83 (59.3%)	226 (32.5%)
2	119 (31.3%)	26 (31.7%)	36 (38.7%)	38 (27.1%)	219 (31.5%)
3	9 (2.4%)	6 (7.3%)	21 (22.6%)	9 (6.4%)	45 (6.5%)
4	51 (13.4%)	8 (9.8%)	5 (5.4%)	2 (1.4%)	66 (9.5%)
5	14 (3.7%)	1 (1.2%)	2 (2.2%)	8 (5.7%)	25 (3.6%)
6	86 (22.6%)	16 (19.5%)	12 (12.9%)	-----	114 (16.4%)

(Table continued)

Table 11. Item Frequency Distributions by Study Site: Time 1
N= 695

Study Variables	Elders Multiple Site	Homecare Multiple Site	Colorectal Cancer	Lung Cancer	Total
Item 7—Activities in the Home					
1	11 (2.9%)	13 (15.9%)	9 (9.7%)	17 (12.1%)	50 (7.2%)
2	8 (2.1%)	7 (8.5%)	9 (9.7%)	26 (18.6%)	50 (7.2%)
3	81 (21.3%)	26 (31.7%)	44 (47.3%)	60 (42.9%)	211 (30.4%)
4	280 (73.7%)	36 (43.9%)	31 (33.3%)	37 (26.4%)	384 (55.3%)
Item 8—Work Activities					
1	2 (0.5%)	11 (13.4%)	9 (9.7%)	20 (14.3%)	42 (6.0%)
2	6 (1.6%)	5 (6.1%)	7 (7.5%)	23 (16.4%)	41 (5.9%)
3	55 (14.5%)	8 (9.8%)	24 (25.8%)	45 (32.1%)	132 (19.0%)
4	317 (83.4%)	58 (70.7%)	53 (57.0%)	52 (37.1%)	480 (69.1%)
Item 9—Recreational and Social Activities					
1	7 (1.8%)	10 (12.2%)	6 (6.5%)	12 (8.6%)	35 (5.0%)
2	17 (4.5%)	11 (13.4%)	14 (15.1%)	21 (15.0%)	63 (9.1%)
3	233 (61.3%)	53 (64.6%)	67 (72.0%)	82 (58.6%)	435 (62.6%)
4	123 (32.4%)	8 (9.8%)	6 (6.5%)	25 (17.9%)	162 (23.0%)
Item 10—Communication					
1	346 (91.1%)	75 (91.5%)	88 (94.6%)	126 (90.0%)	635 (91.4%)
2	26 (6.8%)	5 (6.1%)	4 (4.3%)	10 (7.1%)	45 (6.5%)
3	8 (2.1%)	2 (2.4%)	1 (1.1%)	4 (2.9%)	15 (2.2%)

(Table continued)

Table 11. Item Frequency Distributions by Study Site: Time 2
N= 510

Study Variables	Elders Multiple Site	Homecare Multiple Site	Colorectal Cancer	Lung Cancer	Total
Item 1—Eating/Feeding					
1	171 (48.2%)	11 (23.4%)	-----	19 (17.6%)	201 (39.4%)
2	73 (20.6%)	12 (25.5%)	-----	53 (49.1%)	138 (27.1%)
3	7 (2.0%)	3 (6.4%)	-----	-----	10 (2.0%)
4	86 (24.2%)	11 (23.4%)	-----	34 (31.5%)	131 (25.7%)
5	-----	-----	-----	-----	-----
6	18 (5.1%)	10 (21.3%)	-----	2 (1.9%)	30 (5.9%)
Item 2-- Dressing					
1	187 (52.7%)	28 (59.6%)	-----	43 (39.8%)	258 (50.6%)
2	41 (11.5%)	10 (21.3%)	-----	29 (26.9%)	80 (15.7%)
3	84 (23.7%)	3 (6.4%)	-----	4 (3.7%)	91 (17.8%)
4	23 (6.5%)	3 (6.4%)	-----	11 (10.2%)	37 (7.3%)
5	2 (0.6%)	-----	-----	-----	2 (0.4%)
6	18 (5.1%)	3 (6.4%)	-----	21 (19.4%)	42 (8.2%)
Item 3—Walking					
1	167 (47.0%)	13 (27.7%)	-----	9 (8.3%)	189 (37.1%)
2	103 (29.0%)	22 (46.8%)	-----	57 (52.8%)	182 (35.7%)
3	13 (3.7%)	1 (2.1%)	-----	16 (14.8%)	30 (5.9%)
4	62 (17.5%)	9 (19.1%)	-----	20 (18.5%)	91 (17.8%)
5	10 (2.8%)	1 (2.1%)	-----	5 (4.6%)	16 (3.1%)
6	-----	1 (2.1%)	-----	1 (0.9%)	2 (0.4%)
Item 4—Traveling					
1	177 (49.9%)	16 (34.0%)	-----	22 (20.4%)	215 (42.2%)
2	49 (13.8%)	8 (17.0%)	-----	21 (19.4%)	78 (15.3%)
3	14 (3.9%)	4 (8.5%)	-----	15 (13.9%)	33 (6.5%)
4	64 (18.0%)	6 (12.8%)	-----	18 (16.7%)	88 (17.3%)
5	43 (12.1%)	12 (25.5%)	-----	28 (25.9%)	83 (16.3%)
6	8 (2.3%)	1 (2.1%)	-----	4 (3.7%)	13 (2.5%)

(Table continued)

Table 11. Item Frequency Distributions by Study Site: Time 2
N= 510

Study Variables	Elders Multiple Site	Homecare Multiple Site	Colorectal Cancer	Lung Cancer	Total
Item 5-- Bathing					
1	222 (62.5%)	20 (42.6%)	-----	35 (32.4%)	277 (39.3%)
2	46 (13.8%)	11 (23.4%)	-----	32 (29.6%)	92 (18.0%)
3	15 (4.2%)	3 (6.4%)	-----	14 (13.0%)	32 (6.3%)
4	62 (17.5%)	12 (25.5%)	-----	23 (21.3%)	97 (19.0%)
5	6 (1.7%)	1 (2.1%)	-----	4 (3.7%)	11 (2.2%)
6	1 (0.3%)	-----	-----	-----	1 (0.2%)
Item 6—Toileting					
1	156 (43.9%)	21 (44.7%)	-----	61 (56.5%)	238 (46.7%)
2	104 (29.3%)	16 (34.0%)	-----	34 (31.5%)	154 (30.2%)
3	16 (4.5%)	2 (4.3%)	-----	7 (6.5%)	25 (4.9%)
4	38 (10.7%)	3 (6.4%)	-----	-----	41 (8.0%)
5	5 (1.4%)	1 (2.1%)	-----	4 (3.7%)	10 (2.0%)
6	36 (10.1%)	4 (8.5%)	-----	2 (1.9%)	42 (8.2%)
Item 7—Activities in the Home					
1	118 (33.2%)	8 (17.0%)	-----	11 (10.2%)	137 (26.9%)
2	72 (20.3%)	11 (23.4%)	-----	16 (14.8%)	99 (19.4%)
3	120 (33.8%)	18 (38.3%)	-----	57 (52.8%)	195 (38.2%)
4	45 (12.7%)	10 (21.3%)	-----	24 (22.2%)	79 (15.5%)
Item 8—Work Activities					
1	132 (37.2%)	9 (19.1%)	-----	14 (13.0%)	155 (30.4%)
2	54 (15.2%)	4 (8.5%)	-----	17 (15.7%)	75 (14.7%)
3	91 (25.6%)	8 (17.0%)	-----	41 (38.0%)	140 (27.5%)
4	78 (22.0%)	26 (55.3%)	-----	36 (33.3%)	140 (27.5%)
Item 9—Recreational and Social Activities					
1	132 (37.2%)	13 (27.7%)	-----	12 (11.1%)	157 (30.8%)
2	52 (14.6%)	8 (17.0%)	-----	17 (15.7%)	77 (15.1%)
3	139 (39.2%)	22 (46.8%)	-----	73 (67.6%)	234 (45.9%)
4	32 (9.0%)	4 (8.5%)	-----	6 (5.6%)	42 (8.2%)
Item 10—Communication					
1	317 (89.3%)	46 (97.9%)	-----	100 (92.6%)	463 (90.8%)
2	29 (8.2%)	1 (2.1%)	-----	7 (6.5%)	37 (7.3%)
3	9 (2.5%)	-----	-----	1 (0.9%)	10 (2.0%)

Table 11. Item Frequency Distributions by Study Site: Time 3
N= 457

Study Variables	Elders Multiple Site	Homecare Multiple Site	Colorectal Cancer	Lung Cancer	Total
Item 1—Eating/Feeding					
1	193(57.6%)	18 (42.9%)	-----	11 (13.8%)	222(48.6%)
2	77 (23.0%)	14 (33.3%)	-----	41 (51.3%)	132 (28.9%)
3	3 (0.9%)	-----	-----	1 (1.3%)	4 (0.9%)
4	53 (15.8%)	7 (16.7%)	-----	26 (32.5%)	86 (18.8%)
5	-----	-----	-----	1 (1.3%)	1 (0.2%)
6	9 (2.7%)	3 (7.1%)	-----	-----	12 (2.6%)
Item 2-- Dressing					
1	202 (60.3%)	20 (47.6%)	-----	25 (31.3%)	247 (54.0%)
2	47 (14.0%)	11 (26.2%)	-----	28 (35.0%)	86 (18.8%)
3	57 (17.0%)	3 (7.1%)	-----	5 (6.3%)	65 (14.2%)
4	15 (4.5%)	3 (7.1%)	-----	6 (6.3%)	24 (5.3%)
5	1 (0.3%)	-----	-----	-----	1 (0.2%)
6	13 (3.9%)	5 (11.9%)	-----	16 (20.0%)	34 (7.4%)
Item 3-- Walking					
1	180 (53.7%)	14 (33.3%)	-----	8 (10.0%)	202 (44.2%)
2	88 (26.3%)	15 (35.7%)	-----	33 (41.3%)	136 (29.8%)
3	13 (3.9%)	2 (4.8%)	-----	15 (18.8%)	30 (6.6%)
4	48 (14.3%)	9 (21.4%)	-----	18 (22.5%)	75 (16.4%)
5	6 (1.8%)	2 (4.8%)	-----	5 (6.3%)	13 (2.8%)
6	-----	-----	-----	1 (1.3%)	1 (0.2%)
Item 4—Traveling					
1	196 (58.5%)	16 (38.1%)	-----	12 (15.0%)	224 (49.0%)
2	52 (15.5%)	8 (19.0%)	-----	17 (21.3%)	77 (16.8%)
3	12 (3.6%)	2 (4.8%)	-----	9 (11.3%)	23 (5.0%)
4	46 (13.7%)	7 (16.7%)	-----	22 (27.5%)	75 (16.4%)
5	23 (6.9%)	8 (19.0%)	-----	15 (18.8%)	46 (10.1%)
6	6 (1.8%)	1 (2.4%)	-----	5 (6.3%)	12 (2.6%)

Table 11. Item Frequency Distributions by Study Site: Time 3
N= 457

Study Variables	Elders Multiple Site	Homecare Multiple Site	Colorectal Cancer	Lung Cancer	Total
Item 5-- Bathing					
1	245 (73.1%)	22 (52.4%)	-----	28 (35.0%)	295 (64.6%)
2	37 (11.0%)	9 (21.4%)	-----	18 (22.5%)	64 (14.0%)
3	8 (2.4%)	2 (4.8%)	-----	9 (11.3%)	19 (4.2%)
4	39 (11.6%)	5 (11.9%)	-----	19 (23.8%)	63 (13.8%)
5	6 (1.8%)	4 (9.5%)	-----	6 (7.5%)	16 (2.3%)
6	-----	-----	-----	-----	-----
Item 6-- Toileting					
1	164 (49.0%)	19 (45.2%)	-----	40 (50.0%)	223 (48.8%)
2	110 (32.8%)	12 (28.6%)	-----	25 (31.3%)	147 (32.2%)
3	17 (5.1%)	4 (9.5%)	-----	3 (3.8%)	24 (5.3%)
4	21 (6.3%)	3 (7.1%)	-----	2 (2.5%)	26 (5.7%)
5	1 (0.3%)	-----	-----	4 (5.0%)	5 (1.1%)
6	22 (6.6%)	4 (9.5%)	-----	6 (7.5%)	32 (7.0%)
Item 7—Activities in the Home					
1	158 (47.2%)	13 (31.0%)	-----	8 (10.0%)	179 (39.2%)
2	64 (19.1%)	7 (16.7%)	-----	14 (17.5%)	85 (18.6%)
3	86 (25.7%)	12 (28.6%)	-----	42 (52.5%)	140 (30.6%)
4	27 (8.1%)	10 (23.8%)	-----	16 (20.0%)	53 (11.6%)
Item 8—Work Activities					
1	179 (53.4%)	19 (45.2%)	-----	16 (20.0%)	214 (46.8%)
2	35 (10.4%)	2 (4.8%)	-----	8 (10.0%)	45 (9.8%)
3	75 (22.4%)	3 (7.1%)	-----	27 (33.8%)	105 (23.0%)
4	46 (13.7%)	18 (42.9%)	-----	29 (36.3%)	93 (20.4%)
Item 9—Recreational and Social Activities					
1	159 (47.5%)	11 (26.2%)	-----	7 (8.8%)	177 (38.7%)
2	51 (15.2%)	11 (26.2%)	-----	15 (18.8%)	77 (16.8%)
3	104 (31.0%)	18 (42.9%)	-----	47 (58.8%)	169 (37.0%)
4	21 (6.3%)	2 (4.8%)	-----	11 (13.8%)	34 (7.4%)
Item 10—Communication					
1	307 (91.6%)	39 (92.9%)	-----	70 (87.5%)	416 (91.0%)
2	23 (6.9%)	1 (2.4%)	-----	6 (7.5%)	30 (6.6%)
3	5 (1.5%)	2 (4.8%)	-----	4 (5.0%)	11 (2.4)

Summary of Item Means and Standard Deviations by Study Site

Table 12 summarizes the item distributions as means and standard deviations. This analysis also highlights that study participants were rated highest in social competence, then mobility competence, and finally everyday self-care competence.

Table 12. Item Means and Standard Deviations by Study Site: Time 1
N= 695

Study Variables	Elders Multiple Site	Homecare Multiple Site	Colorectal Cancer	Lung Cancer	Total
Item 1—Eating/Feeding					
Mean	3.35	3.32	2.39	2.36	3.02
SD	1.40	1.67	0.97	1.06	1.40
Item 2—Dressing					
Mean	4.15	3.06	2.61	2.57	3.50
SD	1.76	1.92	1.58	1.83	1.91
Item 3—Walking					
Mean	3.13	2.79	2.35	2.69	2.90
SD	1.12	1.23	0.95	1.16	1.15
Item 4—Traveling					
Mean	5.33	4.04	3.77	3.26	4.55
SD	1.03	1.48	1.48	1.60	1.55
Item 5—Bathing					
Mean	3.52	2.70	2.26	2.48	3.04
SD	1.06	1.31	1.17	1.35	1.29
Item 6—Toileting					
Mean	3.04	2.78	2.73	1.67	2.69
SD	1.92	1.85	1.54	1.06	1.80
Item 7—Activities in the Home					
Mean	3.66	3.04	3.04	2.84	3.34
SD	0.66	1.08	0.91	0.96	0.89
Item 8—Work Activities					
Mean	3.81	3.38	3.30	2.92	3.51
SD	0.47	1.08	0.98	1.05	0.86
Item 9—Recreational and Social Activities					
Mean	3.24	2.72	2.79	2.86	3.04
SD	0.62	0.81	0.66	0.81	0.72
Item 10—Communication					
Mean	1.11	1.11	1.07	1.13	1.11
SD	0.38	0.39	0.29	0.41	0.37

(Table continued)

Table 12. Item Means and Standard Deviations by Study Site: Time 2
N= 510

Study Variables	Elders Multiple Site	Homecare Multiple Site	Colorectal Cancer	Lung Cancer	Total
Item 1—Eating/Feeding					
Mean	2.23	3.15	-----	2.53	2.37
SD	1.50	1.84	-----	1.21	1.50
Item 2—Dressing					
Mean	2.06	1.85	-----	2.62	2.16
SD	1.37	1.40	-----	1.90	1.52
Item 3—Walking					
Mean	2.00	2.28	-----	2.61	2.15
SD	1.21	1.25	-----	1.08	1.21
Item 4—Traveling					
Mean	2.36	2.85	-----	3.19	2.58
SD	1.61	1.71	-----	1.59	1.65
Item 5—Bathing					
Mean	1.83	2.21	-----	2.34	1.97
SD	1.24	1.30	-----	1.24	1.26
Item 6—Toileting					
Mean	2.27	2.13	-----	1.69	2.13
SD	1.61	1.53	-----	1.08	1.52
Item 7—Activities in the Home					
Mean	2.26	2.64	-----	2.87	2.42
SD	1.06	1.01	-----	0.88	1.05
Item 8—Work Activities					
Mean	2.32	3.09	-----	2.92	2.52
SD	1.19	1.20	-----	1.01	1.19
Item 9—Recreational and Social Activities					
Mean	2.20	2.36	-----	2.68	2.32
SD	1.04	0.99	-----	0.75	1.00
Item 10—Communication					
Mean	1.13	1.02	-----	1.08	1.11
SD	0.41	1.15	-----	0.31	0.37

(Table continued)

Table 12. Item Means and Standard Deviations by Study Site: Time 3
N= 457

Study Variables	Elders Multiple Site	Homecare Multiple Site	Colorectal Cancer	Lung Cancer	Total
Item 1—Eating/Feeding					
Mean	1.86	2.19	-----	2.56	2.01
SD	1.28	1.50	-----	1.12	1.30
Item 2—Dressing					
Mean	1.82	2.21	-----	2.70	2.01
SD	1.25	1.66	-----	1.85	1.45
Item 3—Walking					
Mean	1.84	2.29	-----	2.78	2.05
SD	1.14	1.27	-----	1.17	1.21
Item 4—Traveling					
Mean	2.00	2.67	-----	3.33	2.30
SD	1.44	1.68	-----	1.52	1.56
Item 5—Bathing					
Mean	1.58	2.05	-----	2.46	1.78
SD	1.10	1.40	-----	1.38	1.23
Item 6—Toileting					
Mean	1.96	2.17	-----	2.04	1.99
SD	1.37	1.55	-----	1.52	1.41
Item 7—Activities in the Home					
Mean	1.95	2.45	-----	2.83	2.15
SD	1.03	1.17	-----	0.87	1.07
Item 8—Work Activities					
Mean	1.96	2.48	-----	2.87	2.17
SD	1.14	1.44	-----	1.12	1.22
Item 9—Recreational and Social Activities					
Mean	1.96	2.26	-----	2.78	2.13
SD	1.02	0.91	-----	0.80	1.02
Item 10—Communication					
Mean	1.10	1.12	-----	1.18	1.11
SD	0.35	0.45	-----	0.50	0.39

Item-Total Correlations, Internal Consistency, and Mean Scores by Study Site

The item-total correlations, overall scale internal consistency coefficients (Cronbach's alpha), and summary total score statistics by study site are provided in Table 13. Item-total correlations establish the relationship between a single item and all other items in the scale. Kerlinger (1986) recognized that in using the technique of correlating items with total scores, the total score is assumed to be valid. To the extent that an item measures the same thing as the total score does, to that extent the item is valid. If correlations are too low, it suggests that the item is measuring something different from the remaining items. If correlations are too high, it suggests there is considerable overlap and possible redundancy in the items.

For the combined group of participants, except for function 10 (communication), item-total correlations ranged from 0.32 to 0.86, with 78% of items were with the range of 0.60-0.80. Within each study, when function 10 was excluded, item-total correlations ranged from 0.31 to 0.90, with 29% and 56% of items were with the range of 0.30-0.59 and 0.60-0.80, respectively.

For the combined group of participants, the internal consistency reliability coefficients ranged from 0.75 to 0.77 (unstandardized) and 0.88 to 0.92 (standardized to remove effects of skewed item distributions). Within each study, the Cronbach's alphas ranged from 0.71 to 0.78 (unstandardized) and 0.80 to 0.94 (standardized).

Table 13. Item-Total Correlations, Reliabilities and Mean Scores by Study Site: Time 1
N= 695

Study Variables	Elders Multiple Site	Homecare Multiple Site	Colorectal Cancer	Lung Cancer	Total
Function 1	0.41	0.37	0.51	0.61	0.51
Function 2	0.57	0.60	0.66	0.75	0.69
Function 3	0.61	0.70	0.56	0.80	0.66
Function 4	0.58	0.78	0.66	0.81	0.78
Function 5	0.51	0.62	0.61	0.78	0.69
Function 6	0.30	0.45	0.48	0.60	0.43
Function 7	0.55	0.62	0.63	0.66	0.68
Function 8	0.46	0.60	0.59	0.60	0.63
Function 9	0.52	0.66	0.59	0.68	0.63
Function 10	0.07	0.21	0.30	0.36	0.16
Range	0.07-0.61	0.21-0.78	0.30-0.66	0.36-0.81	0.16-0.78
Alpha	0.71	0.75	0.75	0.77	0.75
Std Alpha	0.80	0.87	0.86	0.91	0.88
Range	13-49	10-44	12-50	11-47	10-50
Mean	34.3	28.9	26.3	24.8	30.7
SD	5.8	8.1	6.7	8.3	7.9
Personal Competence Subscale					
Range	8-34	6-31	6-35	6-32	6-35
Mean	22.5	18.7	16.1	15.0	19.7
SD	4.9	6.2	5.1	6.4	6.3
Social Competence Subscale					
Range	5-15	4-14	5-15	4-15	4-15
Mean	11.8	10.2	10.2	9.7	11.0
SD	1.4	2.5	2.1	2.5	2.1

(Table continued)

Table 13. Item-Total Correlations, Reliabilities and Mean Scores by Study Site: Time 2
N= 510

Study Variables	Elders Multiple Site	Homecare Multiple Site	Colorectal Cancer	Lung Cancer	Total
Function 1	0.63	0.50	----	0.63	0.61
Function 2	0.67	0.73	----	0.77	0.69
Function 3	0.70	0.77	----	0.77	0.73
Function 4	0.84	0.81	----	0.81	0.84
Function 5	0.71	0.67	----	0.81	0.74
Function 6	0.32	0.39	----	0.63	0.32
Function 7	0.72	0.80	----	0.73	0.73
Function 8	0.72	0.62	----	0.70	0.72
Function 9	0.72	0.71	----	0.60	0.70
Function 10	0.14	0.43	----	0.33	0.16
Range	0.14-0.84	0.43-0.81	-----	0.33-0.81	0.16-0.84
Alpha	0.76	0.76	----	0.77	0.76
Std Alpha	0.89	0.90	----	0.92	0.89
Range	10-46	10-49	-----	10-48	10-49
Mean	20.7	23.6	-----	24.5	21.7
SD	8.38	8.61	-----	8.28	8.53
Personal Competence Subscale					
Range	6-34	6-35	-----	6-34	6-35
Mean	12.7	14.5	-----	15.0	13.4
SD	6.0	6.3	-----	6.4	6.2
Social Competence Subscale					
Range	4-15	4-14	-----	4-14	4-15
Mean	7.9	9.1	-----	9.5	8.4
SD	2.9	2.7	-----	2.3	2.8

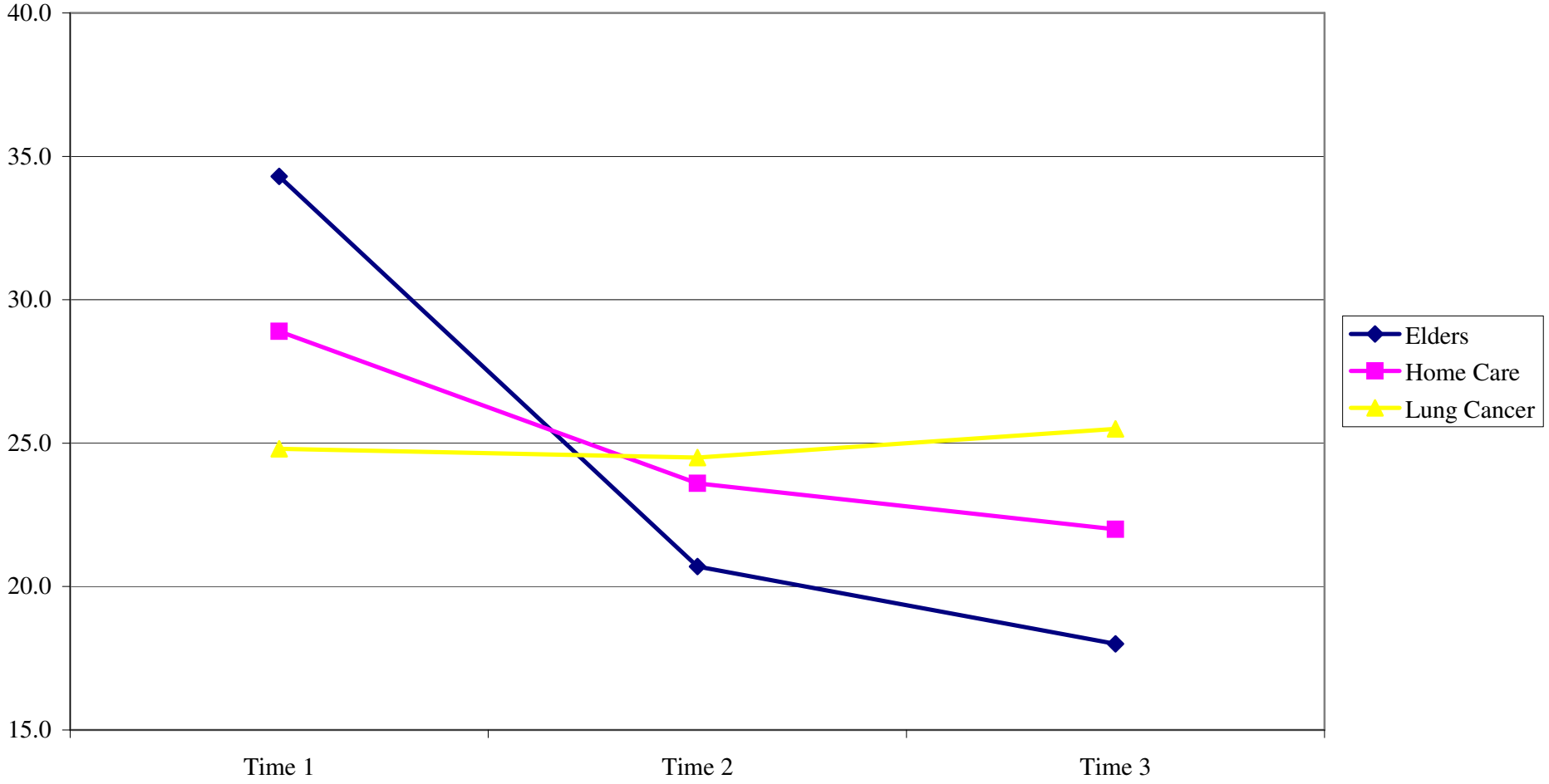
(Table continued)

Table 13. Item-Total Correlations, Reliabilities and Mean Scores by Study Site: Time 3
N= 457

Study Variables	Elders Multiple Site	Homecare Multiple Site	Colorectal Cancer	Lung Cancer	Total
Function 1	0.64	0.73	----	0.73	0.68
Function 2	0.59	0.79	----	0.83	0.69
Function 3	0.72	0.90	----	0.84	0.79
Function 4	0.83	0.88	----	0.85	0.86
Function 5	0.69	0.83	----	0.86	0.77
Function 6	0.34	0.34	----	0.77	0.41
Function 7	0.72	0.82	----	0.68	0.75
Function 8	0.76	0.79	----	0.64	0.76
Function 9	0.66	0.74	----	0.66	0.69
Function 10	0.41	0.17	----	0.54	0.41
Range	0.41-0.83	0.17-0.90	-----	0.54-0.86	0.41-0.86
Alpha	0.76	0.78	----	0.78	0.77
Std Alpha	0.90	0.92	----	0.94	0.92
Range	10-47	10-46	-----	11-47	10-47
Mean	18.0	22.0	-----	25.5	19.7
SD	7.69	9.74	-----	9.39	8.69
Personal Competence Subscale					
Range	6-33	6-32	-----	6-32	6-33
Mean	11.1	13.6	-----	15.9	12.1
SD	5.3	7.1	-----	7.3	6.2
Social Competence Subscale					
Range	4-15	4-15	-----	4-15	4-15
Mean	7.0	8.3	-----	9.6	7.6
SD	2.8	3.3	-----	2.5	3.0

For the combined group of participants, scores of the ESDS ranged from 10 to 50. The average mean scores of the ESDS decreased with time, from 30.7 at time 1 to 19.7 at time 3. Within each study, the mean scores of the ESDS were from 24.8 to 34.3, 20.7 to 24.5, and 18.0 to 25.5 for times 1, 2, and 3, respectively. Changes of mean scores for individual studies and the total study are presented in graph format in Figure 1. As expected, cancer patients in the "Elders multiple site" study were enrolled at an early stage of disease and immediately after surgery, therefore, they had highest scores at the baseline assessment. However, this group of patients improved in their functional status over time as they recovered from their surgery. In contrast, patients in the "Lung Cancer" study were recruited at a later stage of disease, had not had surgery, and had the lowest scores of the ESDS at baseline, compared to other groups of patients. However, as their diseases progressed more quickly than their counterparts, patients in the "Lung Cancer" study deteriorated more prominently in their functional competence. Results from this analysis support further evidence of construct validity of the scale.

Figure 1. Changes of Mean Scores Over Time By Study



Comparisons of Group Means on Demographic and Clinical Characteristics

Table 14 summarizes performance on the scale for various subgroups of study participants. For the total group and numerous subgroups, scores are provided for the 24th, 50th, and 75th percentiles as well as the lowest observed (0 percentile) and highest observed (100th percentile). Percentile scores indicate the percentage of the group that achieved a score identical or lower than the one shown. For example, for the total group at the time 1 baseline assessment, 75% of the participants scored at the level 37 or lower; 25% of the participants scored at 25 or lower. Group sizes, means and standard deviations, and *p* values are also included in Table 14. Because the total ESDS scale distribution is not skewed (skewness values were –0.41. 0.77, and 1.13 for Time 1, Time 2, and Time 3, respectively), most means are close to the 50th percentile or median. The *p* value indicates the result from a t-Test or an ANOVA statistic (depending on the levels of specific variables) that compared subgroup means within a particular demographic characteristic.

At Time 1 assessment, mean scores were significantly different for race (nonwhite patients had higher scores), education (those with 12 or greater than 12 years of education had higher scores), religion (Catholics and those with "other" religions had higher scores), employment (those who were retired or homemakers had higher scores), age (those equal to or greater than 65 years old had higher scores), stage of cancer (those with an early stage cancer had higher scores), and type of cancer (patients with prostate and breast or GYN cancers had higher scores).

At Time 2 and Time 3, there were significant differences in mean scores on: education (those with less than 12 years of education had higher scores), religion (Protestants had higher scores), employment (disabled or unemployed patients had higher scores), stage of cancer (those with advanced cancer had higher scores), and type of cancer (lung cancer patients had higher scores). In addition, at Time 3 assessment, women were also rated higher on the mean scores.

Table 14. Comparisons of Group Means on Demographic and Clinical Characteristics
Time 1: N= 695

Group Percentile	Total Group	Gender		Race	
		Male	Female	White	Nonwhite
100%	50	50	46	50	44
75%	37	36	37	36	38
50%	32	32	32	31	35
25%	25	26	25	24	29
0%	10	10	11	10	10
N	695	325	359	560	139
Mean	30.7	30.8	30.7	30.1	33.2
SD	7.9	7.8	8.1	7.9	7.4
p	-----	0.85		0.0001	

(Table continued)

Table 14. Comparisons of Group Means on Demographic and Clinical Characteristics
Time 1: N= 695

Group Percentile	Living Status		Education		
	Partner	Nopartner	<12 years	12 years	>12 years
100%	49	50	50	46	46
75%	37	37	36	38	36
50%	32	32	29	34	32
25%	24	26	24	27	25
0%	10	11	10	10	12
N	435	255	261	194	240
Mean	30.4	31.3	29.5	32.3	30.7
SD	8.1	7.6	8.1	8.1	7.5
p	0.15		0.001		

(Table continued)

Table 14. Comparisons of Group Means on Demographic and Clinical Characteristics
Time 1: N= 695

Group Percentile	Religion			
	None	Protestant	Catholic	Other
100%	46	49	50	46
75%	36	31	37	37
50%	30	26	34	33
25%	22	21	28	29
0%	10	11	10	12
N	117	124	277	170
Mean	28.9	26.6	32.1	32.7
SD	8.9	8.0	7.4	6.6
p	0.0001			

(Table continued)

Table 14. Comparisons of Group Means on Demographic and Clinical Characteristics
Time 1: N= 695

Group Percentile	Employment					
	Full Time	Part Time	Unemployment	Disabled	Retired	Homemaker
100%	49	43	46	46	50	44
75%	35	34	34	33	38	36
50%	32	28	25	27	35	31
25%	24	20	21	22	31	28
0%	12	11	12	13	10	11
N	115	51	63	84	289	71
Mean	29.8	27.5	26.8	27.3	33.6	31.0
SD	8.1	8.5	8.2	7.9	6.8	7.5
p	0.0001					

(Table continued)

Table 14. Comparisons of Group Means on Demographic and Clinical Characteristics
Time 1: N= 695

Group Percentile	Age				Stage	
	<65	65	66-75	>75	Early stage	Late stage
100%	47	46	50	46	49	47
75%	35	38	37	38	38	36
50%	30	34	33	34	34	31
25%	23	26	27	29	30	23
0%	11	13	10	11	10	10
N	289	33	292	81	288	289
Mean	29.1	32.1	31.7	32.1	33.0	29.7
SD	7.8	8.6	7.7	8.1	7.0	8.5
p	0.0002				0.0001	

(Table continued)

Table 14. Comparisons of Group Means on Demographic and Clinical Characteristics
Time 1: N= 695

Group Percentile	Cancer Site				
	Breast/GYN	Colorectal	Head/Neck	Lung	Prostate
100%	44	50	46	46	44
75%	36	36	37	34	40
50%	33	31	30	28	35
25%	29	26	24	21	33
0%	17	12	10	11	10
N	108	194	42	225	89
Mean	32.6	30.4	29.4	27.7	35.2
SD	6.0	7.5	8.8	8.4	5.4
p	<0.0001				

(Table continued)

Table 14. Comparisons of Group Means on Demographic and Clinical Characteristics
Time 2: N= 510

Group Percentile	Total Group	Gender		Race	
		Male	Female	White	Nonwhite
100%	49	45	49	49	46
75%	27	26	27	27	27
50%	20	19	20	20	21
25%	15	15	15	15	15
0%	10	10	10	10	10
N	510	220	280	398	112
Mean	21.7	21.2	21.9	21.6	22.1
SD	8.5	8.1	8.8	8.5	8.7
p	------	0.36		0.63	

(Table continued)

Table 14. Comparisons of Group Means on Demographic and Clinical Characteristics
Time 2: N= 510

Group Percentile	Living Status		Education		
	Partner	Nopartner	<12 years	12 years	>12 years
100%	49	46	48	49	44
75%	27	28	28	28	25
50%	19	21	21	21	19
25%	15	15	16	14	15
0%	10	10	10	10	10
N	349	159	136	165	209
Mean	21.4	22.5	22.9	22.3	20.5
SD	8.3	9.0	8.9	8.8	7.9
p	0.19		0.02		

(Table continued)

Table 14. Comparisons of Group Means on Demographic and Clinical Characteristics
Time 2: N= 510

Group Percentile	Religion			
	None	Protestant	Catholic	Other
100%	44	48	49	43
75%	22	28	28	27
50%	18	22	21	20
25%	14	17	15	15
0%	10	10	10	10
N	88	74	211	134
Mean	19.2	23.1	22.5	21.4
SD	7.4	8.8	9.0	8.0
p	0.008			

(Table continued)

Table 14. Comparisons of Group Means on Demographic and Clinical Characteristics
Time 2: N= 510

Group Percentile	Employment					
	Full Time	Part Time	Unemployment	Disabled	Retired	Homemaker
100%	45	35	48	44	49	37
75%	22	26	32	32	27	26
50%	17	18	22	26	19	22
25%	14	16	19	18	15	16
0%	10	11	12	10	10	10
N	97	34	40	54	231	52
Mean	18.7	20.3	25.2	25.5	21.6	22.2
SD	7.2	7.1	9.4	8.3	8.8	7.5
p	0.0001					

(Table continued)

Table 14. Comparisons of Group Means on Demographic and Clinical Characteristics
Time 2: N= 510

Group Percentile	Age				Stage	
	<65	65	66-75	>75	Early stage	Late stage
100%	48	43	49	44	45	49
75%	25	28	27	28	23	31
50%	19	19	20	23	17	24
25%	15	16	15	14	13	19
0%	10	10	10	10	10	10
N	200	27	220	63	267	227
Mean	21.2	21.4	22.0	22.7	19.1	24.9
SD	8.2	8.0	8.9	8.8	7.4	8.7
p	0.64				0.0001	

(Table continued)

Table 14. Comparisons of Group Means on Demographic and Clinical Characteristics
Time 2: N= 510

Group Percentile	Cancer Site				
	Breast/GYN	Colorectal	Head/Neck	Lung	Prostate
100%	49	45	44	48	40
75%	25	29	28	28	21
50%	17	21	21	22	17
25%	13	16	17	17	13
0%	10	10	11	10	10
N	101	83	37	171	86
Mean	20.1	22.9	23.4	32.3	18.1
SD	9.0	8.8	8.6	8.1	6.2
p	0.0001				

(Table continued)

Table 14. Comparisons of Group Means on Demographic and Clinical Characteristics
Time 3: N= 457

Group Percentile	Total Group	Gender		Race	
		Male	Female	White	Nonwhite
100%	47	45	47	47	46
75%	24	23	26	24	28
50%	17	16	18	17	17
25%	13	13	13	13	13
0%	10	10	10	10	10
N	457	199	251	353	104
Mean	19.7	18.3	20.5	19.3	20.9
SD	8.7	7.6	9.2	8.4	9.6
p	-----	0.006		0.11	

(Table continued)

Table 14. Comparisons of Group Means on Demographic and Clinical Characteristics
Time 3: N= 457

Group Percentile	Living Status		Education		
	Partner	No partner	<12 years	12 years	>12 years
100%	47	47	47	47	39
75%	24	26	29	25	20
50%	17	18	19	18	16
25%	13	13	14	13	13
0%	10	10	10	10	10
N	308	148	121	143	193
Mean	19.2	20.8	22.3	20.3	17.6
SD	8.1	9.7	9.7	9.1	7.1
p	0.08		0.0001		

(Table continued)

Table 14.Comparisons of Group Means on Demographic and Clinical Characteristics Time 3: N= 457

Group Percentile	Religion			
	None	Protestant	Catholic	Other
100%	46	47	47	40
75%	20	27	25	24
50%	15	20	18	17
25%	12	14	13	13
0%	10	11	10	10
N	82	56	190	126
Mean	17.0	22.4	20.5	18.8
SD	7.0	10.0	9.2	7.8
p	0.0008			

Table 14.Comparisons of Group Means on Demographic and Clinical Characteristics Time 3: N= 457

Group Percentile	Employment					
	Full Time	Part Time	Unemployment	Disabled	Retired	Homemaker
100%	41	40	46	47	47	42
75%	19	23	26	33	23	25
50%	15	18	22	26	16	19
25%	13	14	17	20	12	13
0%	10	10	10	11	10	10
N	93	31	23	49	212	47
Mean	17.3	19.7	23.3	26.7	18.4	20.7
SD	7.4	7.1	9.6	9.9	8.1	8.9
p	0.0001					

Table 14. Comparisons of Group Means on Demographic and Clinical Characteristics
Time 3: N= 457

Group Percentile	Age				Stage	
	<65	65	66-75	>75	Early stage	Late stage
100%	47	45	46	47	43	47
75%	24	24	24	26	20	29
50%	17	18	17	18	15	21
25%	13	14	13	14	12	16
0%	10	10	10	10	10	10
N	180	27	192	58	261	182
Mean	19.5	19.9	19.4	21.4	17.0	23.4
SD	8.8	8.2	8.3	9.7	6.7	9.6
p	0.47				0.0001	

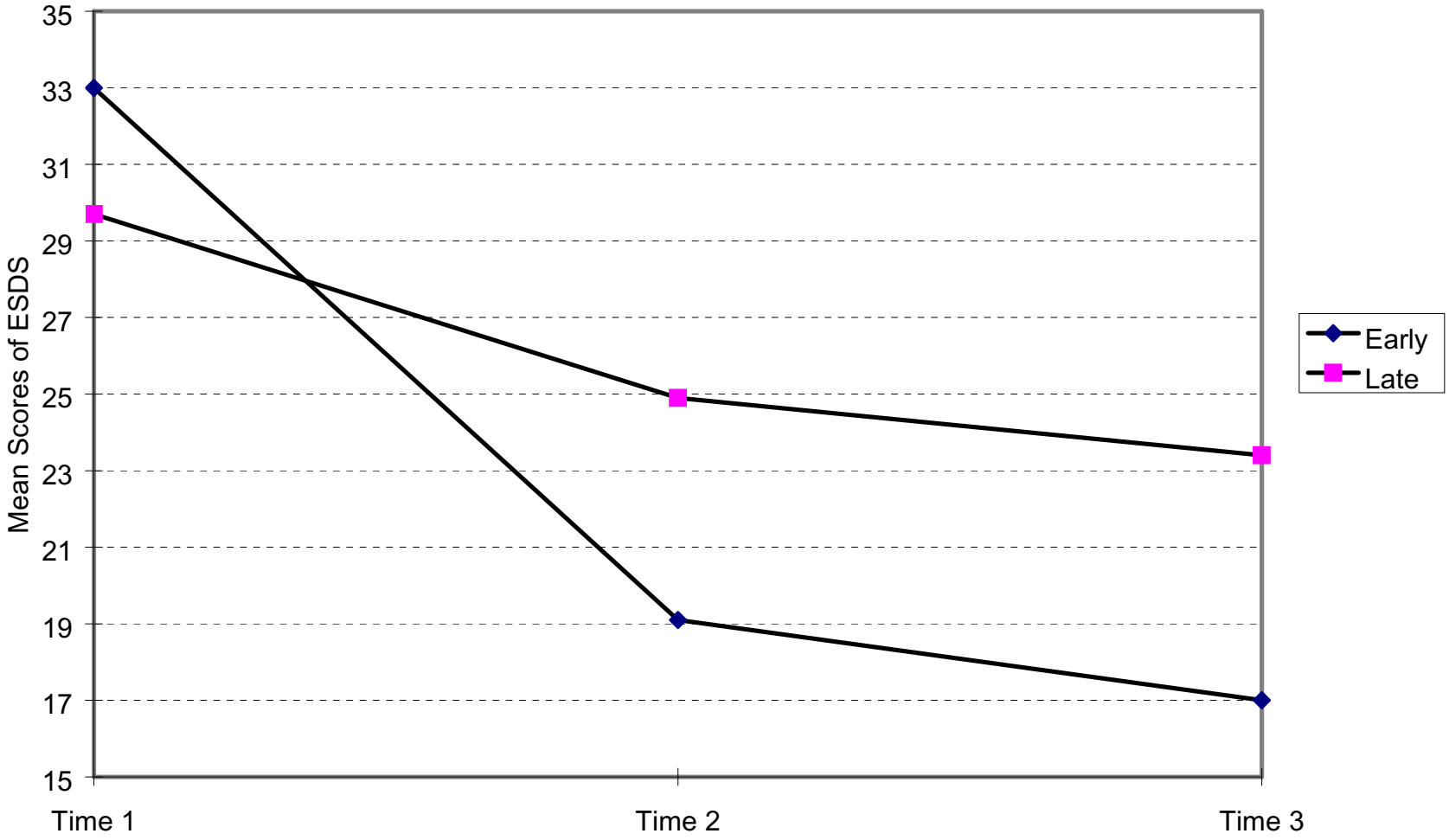
(Table continued)

Table 14. Comparisons of Group Means on Demographic and Clinical Characteristics
Time 3: N= 457

Group Percentile	Cancer Site				
	Breast/GYN	Colorectal	Head/Neck	Lung	Prostate
100%	43	47	46	47	37
75%	21	28	23	29	18
50%	16	17	18	21	14
25%	12	13	14	15	12
0%	10	10	11	10	10
N	97	78	29	138	86
Mean	17.8	20.6	20.5	22.7	15.3
SD	7.7	8.9	8.8	9.4	5.0
p	0.0001				

Specific comparisons of changes of mean scores over time on stage of cancer are presented by graphs in Figure 2. At the baseline assessment, due to the fact that participants with an early stage of cancer were enrolled in the study after their discharge from hospitalization for surgery, this group of patients had higher scores on the ESDS and depended more on other people's help for their daily living. However, as they recovered from their surgeries, they improved in their social dependency. In contrast, participants with advanced cancer deteriorated gradually as time passed and became more dependent in their functional status. Results from this analysis lend further support of construct validity of the scale.

Figure 2. Changes of Mean Scores Over Time by Stage of Cancer in Patients Post-Hospitalization



Tables 15 through 17 provide similar information to earlier tables, but the columns are based on cancer site rather than by study identification. These tables may be helpful for researchers working with a specific patient population for comparative purposes.

Summary of Item Frequency Distributions by Cancer Site

The frequency distributions for each item of the ESDS by cancer site are provided in Table 15. For the total sample and within each study, all options were selected by at least some of the study participants for the majority of items. These results suggest that the content of the 10 items and response options of the ESDS are relevant to newly diagnosed cancer patients. The analysis also showed that response distributions were unimodal. Except for communication (item 10), there were no obvious problems with either floor or ceiling effects. Findings showed that the study participants' functional competence was highest in communication, followed by bathing and toileting. On the other hand, newly diagnosed cancer patients were most socially dependent in traveling, work activities, activities in the home, and recreational and social activities. Such results confirmed the observations from the pilot study of the ESDS that cancer limits the patient's social competence before it affects the patient's ability to perform self-care.

Table 15. Item Frequency Distributions by Cancer Site: Time 1
N= 658

Study Variables	Breast/Gyn N=108	Colorectal N=194	Head/Neck N=42	Lung N=225	Prostate N=89	Total N=658
Item 1—Eating/Feeding						
1	17 (15.7%)	16 (8.3%)	4 (9.5%)	33 (14.7%)	15 (21.4%)	89 (13.5%)
2	17 (15.7%)	72 (37.1%)	6 (14.3%)	103 (45.8%)	39 (43.8%)	237 (36.0%)
3	4 (3.7%)	14 (7.2%)	-----	6 (2.7%)	4 (4.5%)	28 (4.3%)
4	70 (64.8%)	60 (30.9%)	17 (40.5%)	80 (35.6%)	27 (30.3%)	254 (38.6%)
5	-----	-----	1 (2.4%)	1 (0.4%)	-----	2 (0.3%)
6	-----	32 (16.5%)	14 (33.3%)	2 (0.9%)	-----	48 (7.3%)
Item 2-- Dressing						
1	6 (5.6%)	40 (20.6%)	21 (50.0%)	58 (25.8%)	6 (6.7%)	131 (19.9%)
2	6 (5.6%)	33 (17.0%)	5 (11.9%)	66 (29.3%)	7 (7.9%)	117 (17.8%)
3	33 (30.6%)	53 (27.3%)	5 (11.9%)	18 (8.0%)	25 (28.1%)	134 (20.4%)
4	14 (13.0%)	19 (9.8%)	1 (2.4%)	19 (8.4%)	20 (22.5%)	73 (11.1%)
5	-----	-----	-----	1 (0.4%)	1 (1.1%)	2 (0.3%)
6	49 (45.4%)	49 (25.3%)	10 (23.8%)	63 (28.0%)	30 (33.7%)	201 (30.6%)

(Table continued)

Table 15. Item Frequency Distributions by Cancer Site: Time 1
N= 658

Study Variables	Breast/Gyn N=108	Colorectal N=194	Head/Neck N=42	Lung N=225	Prostate N=89	Total N=658
Item 3-- Walking						
1	13 (12.0%)	15 (7.7%)	6 (14.3%)	11 (4.9%)	3 (3.4%)	48 (7.3%)
2	44 (40.7%)	91 (46.9%)	14 (33.3%)	108 (48.0%)	38 (42.7%)	295 (44.8%)
3	4 (3.7%)	15 (7.7%)	6 (14.3%)	16 (7.1%)	2 (2.3%)	43 (6.5%)
4	44 (40.7%)	68 (35.1%)	15 (35.7%)	75 (33.3%)	43 (48.3%)	245 (37.2%)
5	2 (1.9%)	4 (2.1%)	1 (2.4%)	13 (5.8%)	3 (3.4%)	23 (3.5%)
6	1 (0.9%)	1 (0.5%)	-----	2 (0.9%)	-----	4 (0.6%)
Item 4—Traveling						
1	3 (2.8%)	15 (7.7%)	5 (11.9%)	27 (12.0%)	1 (1.1%)	51 (7.8%)
2	2 (1.9%)	14 (7.2%)	3 (7.1%)	35 (15.6%)	1 (1.1%)	55 (8.4%)
3	3 (2.8%)	2 (1.0%)	-----	19 (8.4%)	4 (4.5%)	28 (4.3%)
4	15 (13.9%)	44 (22.7%)	7 (16.7%)	40 (17.8%)	18 (20.2%)	124 (18.8%)
5	26 (24.1%)	65 (33.5%)	15 (35.7%)	52 (23.1%)	23 (25.8%)	181 (27.5%)
6	59 (54.6%)	54 (27.8%)	12 (28.6%)	52 (23.1%)	42 (47.2%)	219 (33.3%)
Item 5—Bathing						
1	6 (5.6%)	40 (20.6%)	12 (28.6%)	50 (22.2%)	8 (9.0%)	116 (17.6%)
2	14 (13.0%)	55 (28.4%)	9 (21.4%)	50 (22.2%)	22 (24.7%)	150 (22.8%)
3	2 (1.9%)	16 (8.3%)	2 (4.8%)	26 (11.6%)	5 (5.6%)	51 (7.8%)
4	85 (78.7%)	75 (38.7%)	17 (40.5%)	86 (38.2%)	48 (53.9%)	211 (32.1%)
5	1 (0.9%)	6 (3.1%)	2 (4.8%)	11 (4.9%)	5 (5.6%)	25 (3.8%)
6	-----	2 (1.0%)	-----	2 (0.9%)	1 (1.1%)	5 (0.8%)
Item 6—Toileting						
1	46 (42.6%)	32 (16.5%)	22 (52.4%)	115 (51.1%)	4 (4.5%)	219 (23.3%)
2	41 (38.0%)	77 (39.7%)	12 (28.6%)	72 (32.0%)	5 (5.6%)	207 (31.5%)
3	4 (3.7%)	27 (13.9%)	1 (2.4%)	13 (5.8%)	-----	45 (6.8%)
4	10 (9.3%)	26 (13.4%)	5 (11.9%)	16 (7.1%)	3 (3.4%)	60 (9.1%)
5	1 (0.9%)	9 (4.6%)	-----	9 (4.0%)	1 (1.1%)	20 (3.0%)
6	6 (5.6%)	23 (11.9%)	2 (4.8%)	-----	76 (85.4%)	107 (16.3%)

(Table continued)

Table 15. Item Frequency Distributions by Cancer Site: Time 1
N= 658

Study Variables	Breast/Gyn N=108	Colorectal N=194	Head/Neck N=42	Lung N=225	Prostate N=89	Total N=658
Item 7—Activities in the Home						
1	4 (3.7%)	15 (7.7%)	6 (14.3%)	21 (9.3%)	2 (2.3%)	48 (7.3%)
2	5 (4.6%)	13 (6.7%)	3 (7.1%)	29 (12.9%)	-----	50 (7.6%)
3	32 (29.6%)	63 (32.5%)	11 (26.2%)	77 (34.2%)	20 (22.5%)	203 (30.9%)
4	67 (62.0%)	103 (53.1%)	22 (52.4%)	98 (43.6%)	67 (75.3%)	357 (54.3%)
Item 8—Work Activities						
1	2 (1.9%)	12 (6.2%)	3 (7.1%)	23 (10.2%)	1 (1.1%)	41 (6.2%)
2	5 (4.6%)	9 (4.6%)	1 (2.4%)	26 (11.6%)	-----	41 (6.2%)
3	16 (14.8%)	38 (19.6%)	7 (16.7%)	54 (24.0%)	12 (13.5%)	127 (19.3%)
4	85 (78.7%)	135 (69.6%)	31 (73.8%)	122 (54.2%)	76 (85.4%)	449 (68.2%)
Item 9—Recreational and Social Activities						
1	6 (5.6%)	9 (4.6%)	4 (9.5%)	13 (5.8%)	2 (2.3%)	34 (5.2%)
2	9 (8.3%)	16 (8.3%)	4 (9.5%)	29 (12.9%)	3 (3.4%)	61 (9.3%)
3	62 (57.4%)	131 (67.5%)	22 (52.4%)	136 (60.4%)	62 (69.7%)	413 (62.8%)
4	31 (28.7%)	38 (19.6%)	12 (28.6%)	47 (20.9%)	22 (24.7%)	150 (22.8%)
Item 10—Communication						
1	95 (88.0%)	179 (92.3%)	39 (92.9%)	208 (92.4%)	81 (91.0%)	602 (91.5%)
2	11 (10.2%)	13 (6.7%)	2 (4.8%)	12 (5.3%)	5 (5.6%)	43 (6.5%)
3	2 (1.9%)	2 (1.0%)	1 (2.4%)	5 (2.2%)	3 (3.4%)	13 (2.0%)

(Table continued)

Table 15. Item Frequency Distributions by Cancer Site: Time 2
N= 478

Study Variables	Breast/Gyn N=101	Colorectal N=83	Head/Neck N=37	Lung N=171	Prostate N=86	Total N=478
Item 1—Eating/Feeding						
1	50 (49.5%)	22 (26.5%)	3 (8.1%)	43 (25.2%)	68 (79.1%)	186 (38.9%)
2	24 (23.8%)	22 (26.5%)	5 (13.5%)	69 (40.4%)	12 (14.0%)	132 (27.6%)
3	3 (3.0%)	3 (3.6%)	1 (2.7%)	2 (1.2%)	-----	9 (1.9%)
4	23 (22.8%)	22 (26.5%)	18 (48.7%)	55 (32.2%)	5 (5.8%)	123 (25.7%)
5	-----	-----	-----	-----	-----	-----
6	1 (1.0%)	14 (16.9%)	10 (27.0%)	2 (1.2%)	1 (1.2%)	28 (5.9%)
Item 2-- Dressing						
1	49 (48.5%)	40 (48.2%)	22 (59.5%)	83 (48.5%)	51 (59.3%)	245 (51.3%)
2	5 (5.0%)	15 (18.1%)	7 (18.9%)	42 (24.6%)	6 (7.0%)	75 (15.7%)
3	29 (28.7%)	19 (22.9%)	2 (5.4%)	9 (5.3%)	23 (26.7%)	82 (17.2%)
4	7 (6.9%)	4 (4.8%)	3 (8.1%)	15 (8.8%)	6 (7.0%)	35 (7.3%)
5	1 (1.0%)	-----	-----	-----	-----	1 (0.2%)
6	10 (9.9%)	5 (6.0%)	3 (8.1%)	22 (12.9%)	-----	40 (8.4%)
Item 3-- Walking						
1	46 (45.5%)	30 (36.1%)	18 (48.7%)	24 (14.0%)	62 (72.1%)	180 (37.7%)
2	27 (26.7%)	30 (36.1%)	12 (32.4%)	87 (50.9%)	18 (20.9%)	174 (36.4%)
3	4 (4.0%)	3 (3.6%)	2 (5.4%)	19 (11.1%)	-----	28 (5.9%)
4	21 (20.8%)	17 (20.5%)	5 (13.5%)	34 (19.9%)	6 (7.0%)	83 (17.4%)
5	2 (2.0%)	3 (3.6%)	-----	6 (3.5%)	-----	11)2.3%)
6	1 (1.0%)	-----	-----	1 (0.6%)	-----	2 (0.4%)
Item 4—Traveling						
1	51 (50.5%)	34 (41.0%)	13 (35.1%)	50 (29.2%)	57 (66.3%)	205 (42.9%)
2	13 (12.9%)	11 (13.3%)	4 (10.8%)	29 (17.0%)	16 (18.6%)	73 (15.3%)
3	5 (5.0%)	5 (6.0%)	3 (8.1%)	20 (11.7%)	-----	33 (6.9%)
4	15 (14.9%)	17 (20.5%)	9 (24.3%)	31 (18.1%)	9 (10.5%)	81 (16.9%)
5	14 (13.9%)	15 (18.1%)	7 (18.9%)	37 (21.6%)	3 (3.5%)	76 (15.9%)
6	3 (3.0%)	1 (1.2%)	1 (2.7%)	4 (2.3%)	1 (1.2%)	10 (2.1%)

(Table continued)

Table 15. Item Frequency Distributions by Cancer Site: Time 2
N= 478

Study Variables	Breast/Gyn N=101	Colorectal N=83	Head/Neck N=37	Lung N=171	Prostate N=86	Total N=478
Item 5—Bathing						
1	59 (58.4%)	47 (56.6%)	18 (48.7%)	69 (40.4%)	68 (79.1%)	261 (54.6%)
2	14 (13.9%)	12 (14.5%)	6 (16.2%)	45 (26.3%)	10 (11.6%)	87 (18.2%)
3	6 (5.9%)	4 (4.8%)	1 (2.7%)	17 (9.9%)	3 (3.5%)	31 (6.5%)
4	19 (18.8%)	18 (21.7%)	12 (32.4%)	36 (21.1%)	4 (4.7%)	89 (18.6%)
5	3 (3.0%)	1 (1.2%)	-----	4 (2.3%)	1 (1.2%)	9 (1.9%)
6	-----	1 (1.2%)	-----	-----	-----	1 (0.2%)
Item 6—Toileting						
1	64 (63.4%)	27 (32.5%)	20 (54.1%)	96 (56.1%)	19 (22.1%)	226 (47.3%)
2	29 (28.7%)	33 (39.8%)	12 (32.4%)	53 (31.0%)	16 (18.6%)	143 (29.9%)
3	-----	6 (7.2%)	-----	9 (5.3%)	10 (11.6%)	25 (5.2%)
4	7 (6.9%)	10 (12.1%)	4 (10.8%)	7 (4.1%)	9 (10.5%)	37 (7.7%)
5	-----	3 (3.6%)	1 (2.7%)	4 (2.3%)	1 (1.2%)	9 (1.9%)
6	1 (1.0%)	4 (4.8%)	-----	2 (1.2%)	31 (36.1%)	38 (7.9%)
Item 7—Activities in the Home						
1	37 (36.6%)	18 (21.7%)	10 (27.0%)	24 (14.0%)	40 (46.5%)	129 (27.0%)
2	16 (15.8%)	22 (26.5%)	12 (32.4%)	25 (14.6%)	19 (22.1%)	94 (19.7%)
3	35 (34.7%)	29 (34.9%)	10 (27.0%)	87 (50.9%)	24 (27.9%)	185 (38.7%)
4	13 (12.9%)	14 (16.9%)	5 (13.5%)	35 (20.5%)	3 (3.5%0	70 (14.6%)
Item 8—Work Activities						
1	43 (42.6%)	19 (22.9%)	7 (18.9%)	29 (17.0%)	47 (54.7%)	145 (30.3%)
2	12 (11.9%)	13 (15.7%)	6 (16.2%)	26 (15.2%)	14 (16.3%)	71 (14.9%)
3	25 (24.8%)	20 (24.1%)	9 (24.3%)	62 (36.3%)	16 (18.6%)	132 (27.6%)
4	21 (20.8%)	31 (37.4%)	15 (40.5%)	54 (31.6%)	9 (10.5%)	130 (27.2%0
Item 9—Recreational and Social Activities						
1	46 (45.5%)	27 (32.5%)	11 (29.7%)	29 (17.0%)	35 (40.7%)	148 (31.0%)
2	12 (11.9%)	11 (13.3%)	5 (13.5%)	27 (15.8%)	16 (18.6%)	71 (14.9%)
3	32 (31.7%)	36 (43.4%)	15 (40.5%)	105 (61.4%)	34 (39.5%)	222 (46.4%)
4	11 (10.9%)	9 (10.8%)	6 (16.2%)	10 (5.9%)	1 (1.2%)	37 (7.7%)
Item 10—Communication						
1	86 (85.2%)	76 (91.6%)	33 (89.2%)	159 (93.0%)	79 (91.9%)	433 (90.6%)
2	13 (12.9%)	5 (6.0%)	2 (5.4%)	9 (5.3%)	7 (8.1%)	36 (7.5%)
3	2 (2.0%)	2 (2.4%)	2 (5.4%)	3 (1.8%)	-----	9 (1.9%)

Table 15. Item Frequency Distributions by Cancer Site: Time 3
N= 428

Study Variables	Breast/Gyn N=97	Colorectal N=78	Head/Neck N=29	Lung N=138	Prostate N=86	Total N=428
Item 1—Eating/Feeding						
1	61 (62.9%)	26 (33.3%)	4 (13.8%)	46 (33.3%)	69 (80.2%)	206 (48.1%)
2	22 (22.7%)	29 (37.2%)	9 (31.0%)	52 (37.7%)	16 (18.6%)	128 (29.9%)
3	1 (1.0%)	-----	-----	2 (1.5%)	-----	3 (0.7%)
4	13 (13.4%)	17 (21.8%)	12 (41.4%)	37 (26.8%)	1 (1.2%)	80 (18.7%)
5	-----	-----	-----	1 (0.7%)	-----	1 (0.2%)
6	-----	6 (7.7%)	4 (13.8%)	-----	-----	10 (2.3%)
Item 2—Dressing						
1	43 (44.3%)	47 (60.3%)	18 (62.1%)	66 (47.8%)	59 (68.6%)	233 (54.4%)
2	14 (14.4%)	14 (18.0%)	6 (20.7%)	38 (27.5%)	10 (11.6%)	82 (19.2%)
3	30 (30.9%)	8 (10.3%)	2 (6.9%)	5 (3.6%)	14 (16.3%)	59 (13.8%)
4	5 (5.2%)	2 (2.6%)	1 (3.5%)	11 (8.0%)	3 (3.5%)	22 (5.1%)
5	-----	-----	-----	-----	-----	-----
6	5 (5.2%)	7 (9.0%)	2 (6.9%)	18 (13.0%)	-----	32 (7.5%)
Item 3—Walking						
1	57 (58.8%)	35 (44.9%)	17 (58.6%)	19 (13.8%)	66 (76.7%)	194 (45.3%)
2	22 (22.7%)	21 (26.9%)	8 (27.6%)	59 (42.8%)	15 (17.4%)	125 (29.2%)
3	4 (4.1%)	3 (3.9%)	-----	21 (15.2%)	-----	28 (6.5%)
4	12 (12.4%)	17 (21.8%)	2 (6.9%)	32 (23.2%)	5 (5.8%)	68 (15.9%)
5	2 (2.1%)	2 (2.6%)	2 (6.9%)	6 (4.4%)	-----	12 (2.8%)
6	-----	-----	-----	1 (0.7%)	-----	1 (0.2%)
Item 4—Traveling						
1	58 (59.8%)	33 (42.3%)	15 (51.7%)	41 (29.7%)	67 (77.9%)	214 (50.0%)
2	12 (12.4%)	14 (18.0%)	3 (10.3%)	28 (20.3%)	13 (15.1%)	70 (16.4%)
3	6 (6.2%)	4 (5.1%)	2 (6.9%)	10 (7.3%)	-----	22 (5.1%)
4	12 (12.4%)	11 (14.1%)	5 (17.2%)	36 (26.1%)	5 (5.8%)	69 (16.1%)
5	8 (8.2%)	15 (19.2%)	2 (6.9%)	18 (13.0%)	1 (1.2%)	44 (10.3%)
6	1 (1.0%)	1 (1.3%)	2 (6.9%)	5 (3.6%)	-----	9 (2.1%)

(Table continued)

Table 15. Item Frequency Distributions by Cancer Site: Time 3
N= 428

Study Variables	Breast/Gyn N=97	Colorectal N=78	Head/Neck N=29	Lung N=138	Prostate N=86	Total N=428
Item 5—Bathing						
1	68 (70.1%)	49 (62.8%)	17 (58.6%)	68 (49.3%)	80 (93.0%)	282 (65.9%)
2	11 (11.3%)	11 (14.1%)	4 (13.8%)	26 (18.8%)	3 (3.5%)	55 (12.9%)
3	2 (2.1%)	3 (3.9%)	3 (10.3%)	10 (7.3%)	1 (1.2%)	19 (4.4%)
4	13 (13.4%)	12 (15.4%)	4 (13.8%)	27 (19.6%)	1 (1.2%)	57 (13.3%)
5	3 (3.1%)	3 (3.9%)	1 (3.5%)	7 (5.1%)	1 (1.2%)	15 (3.5%)
6	-----	-----	-----	-----	-----	-----
Item 6—Toileting						
1	63 (65.0%)	25 (32.1%)	17 (58.6%)	77 (55.8%)	27 (31.4%)	209 (48.8%)
2	27 (27.8%)	35 (44.9%)	10 (34.5%)	40 (29.0%)	27 (31.4%)	139 (32.5%)
3	2 (2.1%)	6 (7.7%)	-----	6 (4.4%)	9 (10.5%)	23 (5.4%)
4	3 (3.1%)	8 (10.3%)	2 (6.9%)	5 (3.6%)	5 (5.8%)	23 (5.4%)
5	-----	-----	-----	4 (2.9%)	1 (1.2%)	5 (1.2%)
6	2 (2.1%)	4 (5.1%)	-----	6 (4.4%)	17 (19.8%)	29 (6.8%)
Item 7—Activities in the Home						
1	41 (42.3%)	31 (39.7%)	11 (37.9%)	28 (20.3%)	58 (67.4%)	169 (39.5%)
2	19 (19.6%)	11 (14.1%)	8 (27.6%)	25 (18.1%)	14 (16.3%)	78 (18.2%)
3	29 (29.9%)	25 (32.1%)	6 (20.7%)	63 (45.7%)	11 (12.8%)	134 (31.3%)
4	8 (8.3%)	11 (14.1%)	4 (13.8%)	22 (15.9%)	3 (3.5%)	48 (11.2%)
Item 8—Work Activities						
1	51 (52.6%)	38 (48.7%)	12 (41.4%)	40 (29.0%)	63 (73.3%0	204 (47.7%)
2	10 (10.3%)	5 (6.4%)	3 (10.3%)	13 (9.4%)	8 (9.3%)	39 (9.1%0
3	22 (22.7%)	15 (19.2%)	7 (24.1%)	43 (31.2%)	13 (15.1%)	100 (23.4%)
4	14 (14.4%)	20 (25.6%)	7 (24.1%)	42 (30.4%)	2 (2.3%)	85 (19.9%)
Item 9—Recreational and Social Activities						
1	56 (57.7%)	31 (39.7%)	7 (24.1%)	28 (20.3%)	44 (51.2%)	166 (38.8%)
2	14 (14.4%)	15 (19.2%)	6 (20.7%)	26 (18.8%)	9 (10.5%)	70 (16.4%)
3	22 (22.7%)	22 (28.2%)	13 (44.8%)	72 (52.2%)	33 (38.4%)	162 (37.9%0
4	5 (5.2%)	10 (12.8%)	3 (10.3%)	12 (8.7%)	-----	30 (7.0%)
Item 10—Communication						
1	85 (87.6%)	70 (89.7%)	28 (96.6%)	126 (91.3%)	81 (91.2%)	390 (91.1%)
2	8 (8.3%)	7 (9.0%)	-----	8 (5.8%)	5 (5.8%)	28 (6.5%)
3	4 (4.1%)	1 (1.3%)	1 (3.5%)	4 (2.9%)	-----	10 (2.3%)

Summary of Item Means and Standard Deviations by Cancer Site

Table 16 summarizes the item distributions as means and standard deviations. The analysis for item means further supports the construct validity of the ESDS. Consistent with the limitations caused by disease or treatments, over time, functional dependence of patients with prostate or head and neck cancer was highest in toileting and eating/feeding, respectively. In addition, dressing was one of the most common difficulties that patients with breast or gynecological cancer required help or assistance with from others. With the progression of disease, colorectal cancer patients gradually became more dependent with eating and feeding activities.

Table 16. Item Means and Standard Deviations by Cancer Site: Time 1
N= 658

Study Variables	Breast/Gyn N=108	Colorectal N=194	Head/Neck N=42	Lung N=225	Prostate N=89	Total N=658
Item 1—Eating/Feeding						
Mean	3.18	3.27	4.12	2.64	2.43	3.02
SD	1.19	1.56	1.68	1.17	1.14	1.40
Item 2—Dressing						
Mean	4.32	3.27	2.62	3.12	4.04	3.50
SD	1.66	1.82	2.06	1.99	1.61	1.91
Item 3—Walking						
Mean	2.82	2.78	2.79	2.90	3.06	2.90
SD	1.20	1.10	1.16	1.15	1.09	1.15
Item 4—Traveling						
Mean	5.19	4.51	4.43	3.94	5.10	4.55
SD	1.18	1.48	1.65	1.72	1.07	1.55
Item 5—Bathing						
Mean	3.56	2.78	2.71	2.84	3.26	3.04
SD	0.93	1.29	1.38	1.32	1.19	1.29
Item 6—Toileting						
Mean	2.05	2.86	1.93	1.81	5.47	2.69
SD	1.35	1.56	1.35	1.09	1.38	1.80
Item 7—Activities in the Home						
Mean	3.50	3.31	3.17	3.12	3.71	3.34
SD	0.76	0.90	1.08	0.96	0.59	0.89
Item 8—Work Activities						
Mean	3.70	3.53	3.57	3.22	3.83	3.51
SD	0.65	0.85	0.86	1.01	0.46	0.86
Item 9—Recreational and Social Activities						
Mean	3.10	3.02	3.00	2.96	3.17	3.04
SD	0.77	0.68	0.88	0.76	0.59	0.72
Item 10—Communication						
Mean	1.04	1.09	1.10	1.10	1.12	1.11
SD	0.40	0.32	0.37	0.37	0.42	0.37

(Table continued)

Table 16. Item Means and Standard Deviations by Cancer Site: Time 2
N= 478

Study Variables	Breast/Gyn N=101	Colorectal N=83	Head/Neck N=37	Lung N=171	Prostate N=86	Total N=478
Item 1—Eating/Feeding						
Mean	2.03	2.98	4.00	2.45	1.37	2.37
SD	1.27	1.77	1.56	1.24	0.91	1.50
Item 2—Dressing						
Mean	2.37	2.08	1.95	2.26	1.81	2.16
SD	1.62	1.37	1.53	1.70	1.06	1.52
Item 3—Walking						
Mean	2.10	2.19	1.84	2.50	1.42	2.15
SD	1.29	1.23	1.04	1.10	0.82	1.21
Item 4—Traveling						
Mean	2.38	2.65	2.89	2.93	1.70	2.58
SD	1.66	1.65	1.68	1.61	1.23	1.65
Item 5—Bathing						
Mean	1.94	2.00	2.19	2.19	1.37	1.97
SD	1.29	1.34	1.35	1.24	0.85	1.26
Item 6—Toileting						
Mean	1.54	2.29	1.76	1.69	3.58	2.13
SD	0.93	1.38	1.09	1.04	2.04	1.52
Item 7—Activities in the Home						
Mean	2.24	2.47	2.27	2.78	1.88	2.42
SD	1.09	1.02	1.02	0.93	0.94	1.05
Item 8—Work Activities						
Mean	2.24	2.76	2.86	2.82	1.85	2.52
SD	1.21	1.19	1.16	1.06	1.07	1.19
Item 9—Recreational and Social Activities						
Mean	2.08	2.33	2.43	2.56	2.01	2.32
SD	1.10	1.05	1.09	0.84	0.93	1.00
Item 10—Communication						
Mean	1.17	1.11	1.16	1.09	1.08	1.11
SD	0.43	0.38	0.55	0.34	0.28	0.37

(Table continued)

Table 16. Item Means and Standard Deviations by Cancer Site: Time 3
N= 428

Study Variables	Breast/Gyn N=97	Colorectal N=78	Head/Neck N=29	Lung N=138	Prostate N=86	Total N=428
Item 1—Eating/Feeding						
Mean	1.65	2.41	3.24	2.24	1.22	2.01
SD	1.03	1.52	1.60	1.20	0.49	1.30
Item 2—Dressing						
Mean	2.18	1.91	1.79	2.24	1.55	2.01
SD	1.33	1.50	1.40	1.70	0.89	1.45
Item 3—Walking						
Mean	1.76	2.10	1.76	2.64	1.35	2.05
SD	1.13	1.26	1.21	1.15	0.76	1.21
Item 4—Traveling						
Mean	2.00	2.54	2.38	2.83	1.37	2.30
SD	1.44	1.65	1.72	1.58	0.85	1.56
Item 5—Bathing						
Mean	1.68	1.83	1.90	2.12	1.14	1.78
SD	1.20	1.27	1.26	13.4	0.60	1.23
Item 6—Toileting						
Mean	1.52	2.17	1.55	1.82	2.73	1.99
SD	0.95	1.27	0.83	1.30	1.85	1.41
Item 7—Activities in the Home						
Mean	2.04	2.21	2.10	2.57	1.52	2.15
SD	1.03	1.12	1.08	0.99	0.85	1.07
Item 8—Work Activities						
Mean	1.99	2.22	2.31	2.63	1.47	2.17
SD	1.16	1.30	1.26	1.20	0.84	1.22
Item 9—Recreational and Social Activities						
Mean	1.75	2.14	2.41	2.49	1.87	2.13
SD	0.98	1.09	0.98	0.91	0.94	1.02
Item 10—Communication						
Mean	1.17	1.12	1.07	1.12	1.06	1.11
SD	0.47	0.36	0.37	0.40	0.24	0.39

Item-Total Correlations, Internal Consistency, and Mean Scores by Cancer Site

The item-total correlations, overall scale internal consistency coefficients (Cronbach's alpha), and summary score statistics by cancer site are provided in Table 17. For each cancer site, when function 10 (communication) was excluded, item-total correlations ranged from 0.32 to 0.88, with 31% and 59% of items were within the range of 0.30-0.59 and 0.60-0.80, respectively. The internal consistency reliability by cancer site ranged from 0.73 to 0.78 (unstandardized) and 0.81 to 0.94 (standardized).

Table 17. Item-Total Correlations, Reliabilities and Mean Scores by Cancer Site: Time 1
N= 658

Study Variables	Breast/Gyn N=108	Colorectal N=194	Head/Neck N=42	Lung N=225	Prostate N=89	Total N=658
Function 1	0.51	0.59	0.53	0.65	0.47	0.51
Function 2	0.60	0.65	0.66	0.74	0.65	0.69
Function 3	0.56	0.69	0.77	0.75	0.57	0.66
Function 4	0.70	0.73	0.78	0.81	0.58	0.78
Function 5	0.40	0.67	0.76	0.79	0.49	0.69
Function 6	0.48	0.32	0.50	0.54	0.32	0.43
Function 7	0.50	0.65	0.76	0.71	0.55	0.68
Function 8	0.49	0.57	0.63	0.64	0.55	0.63
Function 9	0.62	0.63	0.76	0.64	0.57	0.63
Function 10	0.11	0.21	0.12	0.21	-0.01	0.16
Range	0.11-0.70	0.21-0.73	0.12-0.78	0.21-0.81	-0.01-0.65	0.16-0.78
Alpha	0.74	0.75	0.76	0.77	0.73	0.75
Std Alpha	0.83	0.87	0.90	0.91	0.81	0.88
Range	17-44	12-50	10-46	11-46	10-44	10-50
Mean	32.6	30.4	29.4	27.7	35.2	30.7
SD	6.0	7.5	8.8	8.4	5.4	7.9
Personal Competence Subscale						
Range	8-31	6-35	6-32	6-32	6-31	6-35
Mean	21.1	19.5	18.6	17.2	23.4	19.7
SD	4.8	6.0	6.7	6.6	4.6	6.3
Social Competence Subscale						
Range	6-15	5-15	4-15	4-15	4-14	4-15
Mean	11.4	10.9	10.8	10.4	11.8	11.0
SD	1.8	2.0	2.4	2.4	1.4	2.1

(Table continued)

Table 17. Item-Total Correlations, Reliabilities and Mean Scores by Cancer Site: Time 2
N=478

Study Variables	Breast/Gyn N=101	Colorectal N=83	Head/Neck N=37	Lung N=171	Prostate N=86	Total N=478
Function 1	0.70	0.62	0.58	0.62	0.47	0.61
Function 2	0.74	0.75	0.69	0.72	0.58	0.69
Function 3	0.73	0.74	0.71	0.73	0.50	0.73
Function 4	0.87	0.82	0.80	0.82	0.77	0.84
Function 5	0.77	0.71	0.56	0.76	0.63	0.74
Function 6	0.69	0.42	0.67	0.56	0.42	0.32
Function 7	0.75	0.74	0.82	0.71	0.58	0.73
Function 8	0.70	0.71	0.58	0.72	0.63	0.72
Function 9	0.77	0.72	0.78	0.65	0.50	0.70
Function 10	0.18	0.13	0.61	0.11	0.27	0.16
Range	0.18-0.87	0.13-0.82	0.61-0.80	0.11-0.82	0.27-0.77	0.16-0.84
Alpha	0.77	0.77	0.77	0.77	0.74	0.76
Std Alpha	0.92	0.90	0.92	0.90	0.85	0.89
Range	10-49	10-45	11-44	10-48	10-40	10-49
Mean	20.1	22.9	23.4	23.3	18.1	21.7
SD	9.0	8.8	8.6	8.1	6.2	8.53
Personal Competence Subscale						
Range	6-35	6-32	6-29	6-34	6-29	6-35
Mean	12.4	14.2	14.6	14.0	11.3	13.4
SD	6.5	6.4	6.0	6.1	4.5	6.2
Social Competence Subscale						
Range	4-14	4-15	4-15	4-14	4-12	4-15
Mean	7.7	8.7	8.7	9.3	6.8	8.4
SD	3.0	2.8	3.0	2.5	2.4	2.8

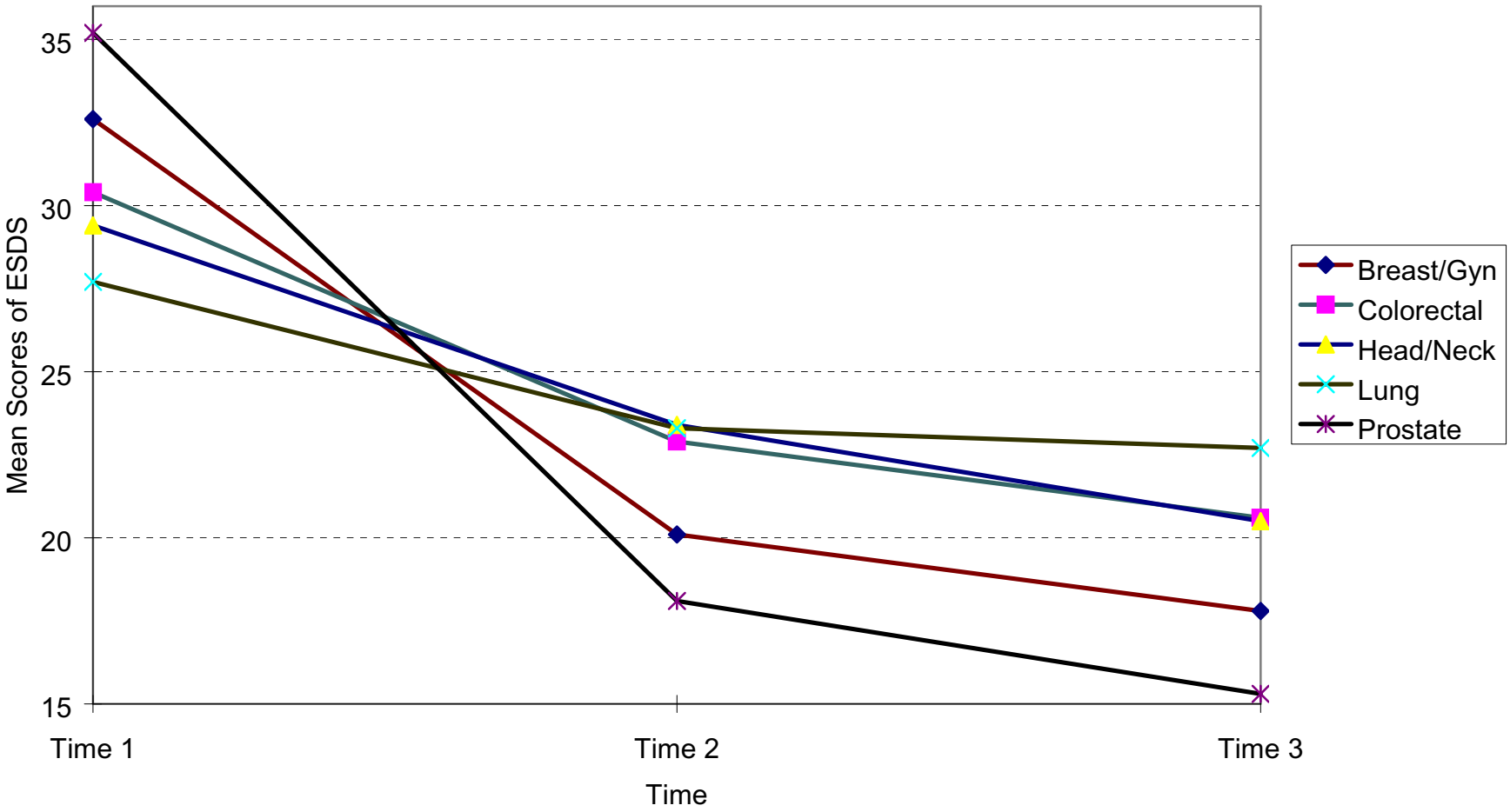
(Table continued)

Table 17. Item-Total Correlations, Reliabilities and Mean Scores by Cancer Site: Time 3
N= 428

Study Variables	Breast/Gyn N=97	Colorectal N=78	Head/Neck N=29	Lung N=138	Prostate N=86	Total N=428
Function 1	0.68	0.60	0.66	0.78	0.47	0.68
Function 2	0.56	0.58	0.75	0.83	0.57	0.69
Function 3	0.74	0.82	0.71	0.81	0.57	0.79
Function 4	0.85	0.88	0.84	0.87	0.64	0.86
Function 5	0.73	0.65	0.67	0.84	0.61	0.77
Function 6	0.46	0.35	0.71	0.70	0.56	0.41
Function 7	0.72	0.79	0.79	0.74	0.54	0.75
Function 8	0.76	0.84	0.76	0.71	0.58	0.76
Function 9	0.68	0.79	0.67	0.70	0.40	0.69
Function 10	0.43	0.41	0.55	0.50	0.14	0.41
Range	0.43-0.85	0.41-0.88	0.55-0.84	0.50-0.87	0.14-0.64	0.41-0.86
Alpha	0.77	0.77	0.77	0.78	0.73	0.77
Std Alpha	0.91	0.91	0.93	0.94	0.84	0.92
Range	10-43	10-47	11-46	10-47	10-37	10-47
Mean	17.8	20.6	20.4	22.7	15.3	19.7
SD	7.7	8.9	8.8	9.4	5.0	8.7
Personal Competence Subscale						
Range	6-28	6-32	6-32	6-32	6-25	6-33
Mean	10.8	13.0	12.6	13.9	9.4	12.1
SD	5.2	6.0	6.3	7.0	3.7	6.2
Social Competence Subscale						
Range	4-15	4-15	4-15	4-15	4-12	4-15
Mean	6.9	7.7	7.9	8.8	5.9	7.6
SD	2.9	3.3	3.1	2.8	2.0	3.0

For each cancer site, the mean scores of the ESDS were 27.7 to 35.2, 18.1 to 23.4, and 15.3 to 22.7 for times 1, 2, and 3, respectively. Changes of mean scores for individual cancer sites and the combined study groups are presented in Figure 3. Prostate and breast/gynecological cancer patients were enrolled in the study immediately after they were discharged following surgery and usually they were discharged with urinary catheters or drainage tubes in place, therefore, they had the highest scores at the baseline assessment in comparison with other groups of patients. However, both groups of patients improved in their functional status over time as they recovered from their surgery. In contrast, lung cancer patients had the lowest scores of the ESDS at the beginning of the study, however, as their diseases progressed more quickly than their counterparts over time, the lung cancer patients deteriorated more prominently in their functional competence. Results from this analysis provide further evidence of construct validity of the scale.

Figure 3. Changes of Mean Scores Over Time by Diagnosis



Chapter 3

Summary of the Use of the Enforced Social Dependency Scale

The ESDS has been used as both an explanatory variable and as a clinical outcome measure in various studies for over twenty years. It has been used in patients with different types of cancer, myocardial infraction, multiple sclerosis, and chronic diseases (diabetes mellitus, hypertension, congestive obstructive pulmonary disease, cardiac disease, and knee, hip, or humeral replacement). The ESDS also has been used in many health care settings, including inpatient units, outpatient clinics (ambulatory), home care, and hospice. There is a substantial body of literature supporting the reliability and validity of the ESDS. Results of studies have supported the usefulness of the ESDS to examine the relationship between functional dependency and quality of life. The clinical utility of using the ESDS as an outcome measurement to investigate the effectiveness of nursing and medical interventions has been documented in a number of studies. Furthermore, the ESDS has been used as a measurement of functional status to demonstrate the impact of functional dependency of cancer patients on their long-term survival. Several groups of researchers have used the ESDS to screen patients who may be in need of intensive nursing care.

Ongoing research is essential to realize the full potential of the ESDS in clinical practice and future research. The development of this manual has provided an opportunity to assess areas that require further research. The major areas for future research involve identifying a cut-off score and establishing the relationship between functional dependence and patient outcomes.

Identification of a cut-off score would be useful for both clinical practice and research. A cut off score facilitates identification of subjects who are significantly dependent on other people's help to perform activities or who are at significant risk of impairment of functional competence. Research is currently underway to identify an appropriate cut-off score based on data obtained from previous studies. Prospective studies that incorporate both the ESDS and other well-validated instruments that were developed specifically for measuring function will be another approach to construct a cut-off score for the ESDS. Prospective clinical trials provide additional opportunities to identify a cut-off score that can screen patients who may be in need of further intervention or who may be at risk for development of adverse outcomes.

Further work is needed to investigate the relationship between enforced social dependency and patient outcomes. Research, to date, shows the promising role of the ESDS in predicting survival, re-hospitalization, and quality of life. Clinical trials targeted toward improving functional independence or empowering family caregivers to provide care tailored at patients' functional dependency will further demonstrate the effectiveness of the ESDS in meeting patients' needs, relieving family's caregiving burden, and improving patients' quality of life.

Copyright Information

The use of the ESDS is encouraged. Although the ESDS is copyrighted to assure quality control, permission to use this instrument is granted upon request. Potential users should contact:

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Appendix A. Enforced Social Dependency Scale—Initial Interview Guide (Form I)

The Enforced Social Dependency Scale (ESDS) is recommended to be used with people who have recently experienced an illness, such as cancer, stroke, or heart attack. Form I is to be used to evaluate the patient's function initially after illness. If the scale is administered beyond the initial illness, the questions need to be asked within the last week.

Instructions:

The Enforced Social Dependency Scale was developed to determine the extent to which the patient's dependence on external sources of support has changed during illness. Dependence is defined in terms of a number of specific functional items, such as bathing and eating. Based on the questions asked in the interview, the interviewers should be able to rate how the patient is faring with respect to these functional activities on the Enforced Social Dependency Scale. To aid you in this effort, verbal descriptions of the levels of the items have been provided along with explicit definitions of how defining terms are being used. You should familiarize yourself with the levels of the Enforced Social Dependency Scale before beginning your interview.

In order to determine the appropriate location on the item codes for a particular person, a set of suggested interview questions has been provided for each scale item (with the exception of the consciousness item). The first question is general and open-ended. It may be that the patient will give enough information in response to this question that no further questions are necessary for that particular item. If this is so, simply record the information and move on to the next item. If more information is needed to make the proper determination, continue with the more detailed questions (marked "e.g.") are given for some of the items. The general principle is this: Ask as many of the questions as necessary to determine where a patient belongs on a particular code for that item. Then record this information and move on to the next item.

In general, you should **not** accept a quick answer that "everything is normal (usual)." The patient may not understand how you are using your terms. This is one reason for using the more specific questions. Consider an example: In response to your general question, a patient says that his bathing is normal (usual). After further probing, however, he reveals that he recently requires grab rails to get in and out of the tub. This might seem perfectly normal (usual) to him. This item would be coded a "3", bathes with use of equipment, rather than a "1", usual bathing activity, no change.

On the other hand, it may quickly become apparent to you that a particular aspect of the patient's behavior is normal (usual). A patient who has already told you he plays tennis every day will probably not require assistance in walking (to take an extreme example). Once you have acquired a little experience with the items and codes, observation and inference may be used to reduce the number of questions asked for each item.

Interview Guide for Enforced Social Dependency Scale

TO THE PATIENT:

In general, I would like to know how your present activities differ from your usual patterns prior to your illness. I'm interested in what effects your illness has had on your day-to-day living. To make sure I find out as much about this as I can, I'm going to ask you a number of specific questions about what a typical day is like for you.

(Eating)

1. What about eating, for example? How do your present eating habits differ from what was usually for you before your illness?
   a. Does it take you more time to eat?
   b. Do you eat at the same times as you used to? Do you eat in the same place (e.g., at the table)?
   c. Do people bring food to you more often?
   d. Are you able to cut your own food?
   e. Is pouring milk or coffee a problem for you?

(OPTIONAL)

Are there any special eating utensils, such as enlarged fork handles or non skid plates, that you use and find helpful?

(Dressing)

2. Do you have problems dressing yourself now that you didn't have before your illness (e.g., bending to put on shoes, stretching to pull something over your head); has illness made it harder to get dressed?
   a. Does it take more time to get dressed?
   b. Do you need help in putting on some of your clothes—fastening buttons, for example, or lacing your shoes?
   c. Do you wear special clothes, or use special equipment, to make dressing easier?
   d. Are there days you don/t get dressed, but wear your bed clothes? About how many days a week, would you say?

(Walking)

3. Do you walk and get about in the same way you did before your illness?
   a. Does it take more time to walk somewhere? Is your walking more deliberate (i.e., cautious or careful)?
   b. Are you ever assisted in getting about?
      Has the doctor restricted your walking in any way? (e.g., do you need to be accompanied when you go on walks)?
   c. Do you use special equipment to help you walk? e.g., Do you use a cane or a crutch?
      Do you wear braces or special shoes?
      Do you take elevators more than you used to?

(Travel)

4. How do your present travel and transportation patterns differ from what was usual for you before your illness?
    a. How do you get to the doctor for your medical appointments?
    b. Do you drive a car or take a bus as often as you used to?
    c. What kinds of places do you drive to (or go to)?
    d. Are there places you used to drive to (or ride to), you don't go to as often now (non-essential trips, e.g., going out for dinner, shopping, etc.)?

(Bathing)

5. How do your present bathing patterns differ from what was usual for you before your illness?
    a. About how often—how many times a week—do you bathe now?
    b. How do you usually bathe? Of the___ times a week you bathe, how many are tub baths? ____ Showers?____ Sponge baths?____(e.g., washing yourself down with a close or sponge)?
    c. Does it take you more time to bathe?
    d. Are you assisted in bathing by other people?
    e. Are there special devices or equipment that you use and find helpful?
    f. What about shaving? Do you shave as often? Or have you changed how you shave (e.g., manual razor to electric)?
    g. How do you care for you hair? Number of times washed? (e.g., barber shop or beauty shop)?

(Toileting)

6. Are you able to get to the bathroom and use it in the same way as you did before your illness?
    a. Have your habits changed? E.g., are you having trouble with constipation or diarrhea?
    b. Do you need to get up more often at night?
    c. Do you need help to get up more often at night?
    e.g. Does someone assist you in walking to the bathroom or in the bathroom?
    d. Do you need special equipment, such as grab-rails or a raised toilet seat, portable commode, bedpan or urinal?

(Role in the Home)

7. Can you describe what your primary responsibilities have been in your home? Has this changed since your illness? If yes, in what ways?
    a. Who prepares the meals? If the patient does, ask if the illness has affected this activity.
    b. Who does the shopping? If the patient does, ask if the illness has affected this activity.
    c. Who does the laundry? If the patient does, ask if the illness has affected this activity.
    d. Who cleans the house? If the patient does, ask if the illness has affected this activity.
    e. Who does repairs around the house? If the patient does, ask if the illness has affected this activity.
    f. Who does the yardwork? If the patient does, ask if the illness has affected this activity.
    g. Who runs errands? If the patient does, ask if the illness has affected this activity.

8. (Work Role) Complete a, b, or c

a. Do you work? That is , do you receive pay for the work you do? If yes:
    1. Are you presently working? What kind of work are you doing?
    2. Are there some things at work you used to do that you aren't doing now?

b. If you don't work, did you stop working for pay because of your current illness? If yes:
    1. What kind of things do you do <u>now</u> that you think of as work (that is, things you are responsible for, such as chores around the house, volunteer or club duties)?
    2. Are there some things you used to do that you aren't doing now?

c. If you have never worked for pay or have not worked for pay for a considerable period of time unrelated to current illness:
    1. What kind of things have you done that you consider work (that is, things you are responsible for, such as chores—yardwork, repairs, cooking, cleaning, shopping—or volunteer work)?
    2. Are there some things you used to do that you aren't doing now?

9. (Recreational and Social Role)

a. What kinds of things do you do for recreation or just for fun? What about TV
b. Has this changed in any way since your illness?
c. How much contact do you have with people not a part of your family and where does this occur?
d. Do you keep in touch with your friends like you used to?
e. Are there things you'd like to do in the way of recreation or entertainment that you aren't doing right now?
f. What do you do (do you plan to do) on the most recent (upcoming) major holiday?
g. Have there been any changes in your sexual activity/ability?

10. (Communication—Consciousness scale): Interviewer makes a judgment for this item

a. Patient responds to interviewer in normal, coherent fashion.
b. Patient responds to interviewer's questions but adds much tangential or irrelevant information.
c. Patient does not respond directly to interviewer; requires much prompting to elicit any answer or maintain attention.

Appendix B. Enforced Social Dependency Scale—Initial Interview Guide (Form II)

The Enforced Social Dependency Scale (ESDS) is recommended to be used with people who have recently experienced an illness, such as cancer, stroke, or heart attack. Form I should be used to evaluate the patient's function initially after illness. If the scale is administered beyond the initial illness, Forum II should be used to evaluate the patient's function over time. The questions need to be asked during the last week.

Instructions:

The Enforced Social Dependency Scale was developed to determine the extent to which the patient's dependence on external sources of support has changed during illness. Dependence is defined in terms of a number of specific functional items, such as bathing and eating. Based on the questions asked in the interview, the interviewer should be able to rate how the patient is faring with respect to these functional activities on the Enforced Social Dependency Scale. To aid you in this effort, verbal descriptions of the levels of the items have been provided along with explicit definitions of how defining terms are being used. You should familiarize yourself with the levels of the Enforced Social Dependency Scale before beginning your interview.

In order to determine the appropriate location on the item codes for a particular person, a set of suggested interview questions has been provided for each scale item (with the exception of the consciousness item). The first question is general and open-ended. It may be that the patient will give enough information in response to this question that no further questions are necessary for that particular item. If this is so, simply record the information and move on to the next item. If more information is needed to make the proper determination, continue with the more detailed questions (marked "e.g.") are given for some of the items. The general principle is this: Ask as many of the questions as necessary to determine where a patient belongs on a particular code for that item. Then record this information and move on to the next item.

In general, you should **not** accept a quick answer that "everything is normal (usual)." The patient may not understand how you are using your terms. This is one reason for using the more specific questions. Consider an example: In response to your general question, a patient says that his bathing is normal (usual). After further probing, however, he reveals that he recently requires grab rails to get in and out of the tub. This might seem perfectly normal (usual) to him. This item would be coded a "3", bathes with use of equipment, rather than a "1", usual bathing activity, no change.

On the other hand, it may quickly become apparent to you that a particular aspect of the patient's behavior is normal (usual). A patient who has already told you he plays tennis every day will probably not require assistance in walking (to take an extreme example). Once you have acquired a little experience with the items and codes, observation and inference may be used to reduce the number of questions asked for each item.

Interview Guide for Enforced Social Dependency Scale

TO THE PATIENT:

In general, I would like to know how your present activities differ from your usual patterns prior to your illness. I'm interested in what effects your illness has had on your day-to-day living. To make sure I find out as much about this as I can, I'm going to ask you a number of specific questions about what a typical day is like for you.

(Eating)

1. What about eating, for example? How are your present eating habits?
    a. Does it take you more time to eat during the last week?
    b. Do you eat at the same times as you used to? Do you eat in the same place (e.g., at the table)?
    c. Do people bring food to you more often?
    d. Are you able to cut your own food?
    e. Is pouring milk or coffee a problem for you?

(OPTIONAL)

Are there any special eating utensils, such as enlarged fork handles or non skid plates, that you use and find helpful?

(Dressing)

2. What about dressing (e.g., bending to put on shoes, stretching to pull something over your head).
    a. Does it take more time to get dressed within the last week?
    b. Do you need help in putting on some of your clothes—fastening buttons, for example, or lacing your shoes?
    c. Do you wear special clothes, or use special equipment, to make dressing easier?
    d. Are there days you don/t get dressed, but wear your bed clothes? About how many days a week, would you say?

(Walking)

3. Do you walk and get about?
    a. Does it take more time to walk somewhere? Is your walking more deliberate (i.e., cautious or careful)?
    b. Are you ever assisted in getting about?
    Has the doctor restricted your walking in any way? (e.g., do you need to be accompanied when you go on walks)?
    c. Do you use special equipment to help you walk?
    e.g., Do you use a cane or a crutch?
    Do you wear braces or special shoes?
    Do you take elevators more than you used to?

(Travel)

4. What about your travel and transportation patterns within the last week?
   a. How do you presently get to the doctor for your medical appointments?
   b. Do you drive a car or take a bus as often as you used to?
   c. What kinds of places do you drive to (or go to)?
   d. Are there places you used to drive to (or ride to), you don't go to as often now (non-essential trips, e.g., going out for dinner, shopping, etc.)? within the last week?

(Bathing)

5. How about your present bathing patterns within the last week?
   a. About how often—how many times a week—do you bathe now?
   b. How do you bathe? Of the___ times a week you bathe, how many are tub baths? Showers?____ Sponge baths?____(e.g., washing yourself down with a close or sponge)?
   c. Does it take you more time to bathe?
   d. Are you assisted in bathing by other people? e.g., Are water and equipment brought to you? Do you need help in getting in and out of the tube or shower? Do you need help in washing hard-to-reach areas, such as your back?
   e. Are there special devices or equipment that you use and find helpful?
   f. What about shaving? Do you shave as often? Or have you changed how you shave (e.g., manual razor to electric)?
   g. How do you care for you hair? Number of times washed? (e.g., barber shop or beauty shop)?

(Toileting)

6. What about your present bath room habits?
   a. Have your habits changed within the last week? e.g., are you having trouble with constipation or diarrhea?
   b. Do you need to get up more often at night?
   c. Do you need help to get up more often at night?
      e.g. Does someone assist you in walking to the bathroom or in the bathroom?
   d. Do you need special equipment, such as grab-rails or a raised toilet seat, portable commode, bedpan or urinal?

(Role in the Home)

7. Can you describe what your primary responsibilities have been in your home now?
   a. Who prepares the meals? If the patient does, ask if within the last week.
   b. Who does the shopping? If the patient does, ask if within the last week.
   c. Who does the laundry? If the patient does, ask if within the last week.
   d. Who cleans the house? If the patient does, ask if within the last week.
      Who does repairs around the house? If the patient does, ask if within the last week.
   e. Who does the yardwork? If the patient does, ask if within the last week.
   f. Who runs errands? If the patient does, ask if within the last week.
   g. Are there some things you used to do that you are not doing now?

8. (Work Role) Complete a, b, or c

a. Do you work? That is, do you receive pay for the work you do? If yes:
    1. Are you presently working? What kind of work are you doing?
    2. Are there some things at work you used to do that you aren't doing now?

b. If you don't work, did you stop working for pay because of your current illness? If yes:
    1. What kind of things do you do now that you think of as work (that is, things you are responsible for, such as chores around the house, volunteer or club duties)?
    2. Are there some things you used to do that you aren't doing now?

c. If you have never worked for pay or have not worked for pay for a considerable period of time unrelated to current illness:
    1. What kind of things have you done that you consider work (that is, things you are responsible for, such as chores—yardwork, repairs, cooking, cleaning, shopping—or volunteer work)?
    2. Are there some things you used to do that you aren't doing now?

9. (Recreational and Social Role)

a. What kinds of things do you do for recreation or just for fun? What about TV
b. What have you done within the last week?
c. How much contact do you have with people not a part of your family within the last week, and where does this occur?
d. Do you keep in touch with your friends?
e. Are there things you'd like to do in the way of recreation or entertainment that you aren't doing right now?
f. What do you do (do you plan to do) on the most recent (upcoming) major holiday?

10. (Communication—Consciousness scale): Interviewer makes a judgment for this item

a. Patient responds to interviewer in normal, coherent fashion.
b. Patient responds to interviewer's questions but adds much tangential or irrelevant information.
c. Patient does not respond directly to interviewer; requires much prompting to elicit any answer or maintain attention.

Appendix C. Coding Instructions for Enforced Social Dependency Scale (ESDS)

1. Eating/Feeding

____ 1 Feeds self without help of any kind—No restrictions.

____ 2 Feeding involves some minor pre-existing restriction (not severe enough to be coded 3-6) or some minor change since illness (also not severe enough to be coded 3-6).

____ 3 Feeds self with help of a device or equipment.

____ 4 Feeds self with help of another person or major changes in pattern of eating.

____ 5 Spoon fed (unable to participate).

____ 6 Does not eat or is tube fed.

2. Dressing

____ 1 Dresses regularly in street clothes without help of any kind or use of special equipment.

____ 2 Dressing involves some minor pre-existing restriction (not severe enough to be coded 3-6) or some minor change since illness (also not severe enough to be coded 3-6).

____ 3 Dresses with help of equipment or device; loose clothing.

____ 4 Dresses with help of another person in street clothes or by self, but with major changes in the pattern of dressing, designed to maintain some degree of independence.

____ 5 Is regularly dressed in street clothes only by the help of another person, is unable to participate in dressing.

____ 6 Is usually not dressed in street clothes.

3. Walking

____ 1 Walks without help of any kind—No restrictions.

____ 2 Walking involves some minor pre-existing restriction (not severe enough to be coded 3-6) or some minor change since illness (also not severe enough to be coded 3-6).

____ 3 Walks with help of equipment or device.

____ 4 Walks by self or with help of another person (s) (may include equipment or device); walking is definitely limited, e.g. only to bathroom, room to room, or to car.

____ 5 Does not walk, can take a few steps with help (also using equipment or person).

____ 6 Unable to take any steps at all (when this activity disrupts comfort).

4. Travel

____ 1 Travel freely without help, drives car or takes bus—No restrictions.

____ 2 Travel involves some minor pre-existing restriction (not severe enough to be coded 3-6) or some minor change since illness (also not severe enough to be coded 3-6).

____ 3 Travel <u>freely</u> with help from another person. Takes a taxi, but not a bus.

____ 4 Takes occasional non-essential trips out of home, relies on self or requires help from another person. Major change from driving patterns.

____ 5 Take only necessary trips (medically-related; grocery shopping) away from the home; relies on self or requires the help of another person.

____ 6 Confined to home.

5. Bathing

____ 1 Bathes without any help—No restrictions.

____ 2 Bathes involves some minor pre-existing restriction (not severe enough to be coded 3-6) or some minor change since illness (also not severe enough to be coded 3-6).

____ 3 Bathes with help of equipment.

____ 4 Bathes with help of another person, or by self but with major changes in the pattern of bathing, designed to maintain some degree of independence.

____ 5 Is bathed (unable to participate except for face and hands).

____ 6 Is not bathed (when this activity disrupts comfort).

6. Toileting

____ 1 Use toilet room without help of any kind—No restrictions.

____ 2 Use of toilet involves some minor pre-existing restriction (not severe enough to be coded 3-6) or some minor change since illness (also not severe enough to be coded 3-6).

____ 3 Use toilet room with help of another person (may include use of special equipment).

____ 4 Uses portable commode by self or with help of another person.

____ 5 Use bedpan or urinal by self or with help of another person.

____ 6 Incontinent, uses catheter, or uncontrolled, frequent urination (colostomy not under control).

7. Activities in the Home

____ 1 Usual activities—no change in quantity or quality of activities characterizing usual household role performance.

____ 2 Modified activity—all activities continue as before but with some limitations in degree.

____ 3 Restricted activity—some activities characterizing usual household role can no longer be performed.

____ 4 No activity—major activities defining role are no longer being performed.

8. Activities in the Work

8A. Work Activities for Person Employed Outside Home

____ 1 Usual activities—no change in quantity or quality of activities characterizing work role; continues to work.

____ 2 Modified activity—all activities continue as before but with some limitations in degree; continues to work.

____ 3 Restricted activity—some activities characterizing work role can no longer be performed; work half as much time as before or less.

____ 4 No activity—major activities defining role are no longer being performed.

Note: Taking occasional time off or one to two days off each month is coded as two if work is still being done. Coded as 4 even if person continues to be paid

8B. Work-Type Activities if Forced to Retire Because of Illness

____ 1 Usual activities—no change in quantity or quality of activities characterizing work role.

____ 2 Modified activity—all activities continue as before but with some limitations in degree.

____ 3 Restricted activity—some activities characterizing work role can no longer be performed; work half as much time as before or less.

____ 4 No activity—major activities defining role are no longer being performed.

8C. Work-Type Activities for Retired Person (before illness) or Homemaker

____ 1 Usual activities—no change in quantity or quality of activities characterizing work role.

____ 2 Modified activity—all activities continue as before but with some limitations in degree.

____ 3 Restricted activity—some activities characterizing work role can no longer be performed; work half as much time as before or less.

____ 4 No activity—major activities defining role are no longer being performed.

9. Recreational and Social Activities

____ 1 Usual activities—no change in quantity or quality of recreation and socializing.

____ 2 Modified activity—all recreational and social activities continue as before but with some limitations in degree.

____ 3 Restricted activity—some recreational and social activities have ceased altogether.

____ 4 No activity—no recreational or social activities at all.

10. Communication

____ 1 Responds to interviewer in normal, coherent fashion.

____ 2 Responds to interviewer's questions but adds much tangential or irrelevant information; has occasional lapses of attention or memory.

____ 3 Does not respond directly to interviewer, requires much prompting to elicit any answer or maintain attention.

Definitions of Terms for Coding

I. Personal Competence

1. Eating/Feeding

This item refers to the physical aspects of eating and feeding and also to changes in appetite, taste, or smell that affect the quantity and pattern of eating. Include changes that occur as reactions to treatment or are manifestations of the illness process.

Without help of any kind means, the patient receives no assistance from another person nor from the use of special devices. He cuts food, butters bread, pours beverages, handles utensils, and conveys food to mouth.

Minor restriction/minor change means, for example, the patient eats slowly, eats small amounts, eats frequently. Interviewers ask about change since illness as another basis for distinguishing between code 1 and 2.

Help from another person means another person helps the patient in food retrieval, preparation, and/or eating as a result of the patient's health condition; Example: Husband now cooks meals

Patient has food brought to him on a tray.

Patient needs help in cutting meat, buttering bread, opening cartons, pouring milk, etc.

Devices used:

utensils specifically adapted such as enlarged handles, rocker spoons, forked, knives; plate splint

suction dishes or nonskid plates; T.V. tray

Does not eat means person eats nothing, where due to lack of desire, level of consciousness or treatment effects.

Is tube fed includes when patient is fed a prescribed liquid diet via a naso-oral-gavage tube or gastrogavage tube and is fed parenterally a prescribed sterile solution by clysis or intravenously.

2. Dressing

Without help of any kind means, for example, the patient receives no assistance from another person nor from the use of equipment.

Minor restriction/minor change means, for example, the patient dresses slowly, occasionally doesn't feel up to getting dressed, experiences some unsteadiness or pain while dressing which slows process. Includes changes in types of clothes worn, e.g. more clothing. Interviewers ask about change since illness as another basis for distinguishing between codes 1 and 2.

Help from another person means another person helps the patient in:

- obtaining the clothing for the patient, i.e., hospital gown
- fastening hooks, buttons, or zippers
- putting on clothes, socks, shoes
- putting on brace or artificial limbs
- observing, supervising, or teaching him to dress himself

Equipment and devices used include:

- pre-existing conditions
- long-handled shoes horn, stocking pull
- zipper pulls, velcro fasteners
- adapted clothing, e.g., wide pant legs, front hooking bra, special clothing for radiation reactions
- walker with attached clothing basket to get to and to carry clothes
- leans against wall, or against furniture; sits on bed

If a patient spends the day in his bed clothes more than two or three times a week, # 6 rather # 2, is the appropriate scale category. Dresses only for trips outside.

3. Walking

Without help of any kind means the patient receives no assistance or supervision from another person, nor from use of equipment or a device.

Minor restriction/minor change means, for example, the patient's walking is slow, deliberate, limited/reduced. Interviewers ask about change since illness as another basis for distinguishing between codes 1 and 2.

Help from another person with walking implies a one-to-one relationship of helper and patient. Examples are physical support, guarding, guiding, protecting, and supervising; these are considered help if the patient walks only with this help. Observation is regarded as help in special situations such gait training program, or

if walking is permitted only with an observer present. Includes needing to be accompanied on longer walks.

Equipment or devices used for walking are several kinds. Some may be worn by individuals, others not. Examples of equipment or devices are leg braces, splints, canes, crutches, special shoes, back braces, walkers, and elevators.
Architectural fixtures such as handrails, or furniture such as non-wheeling chairs, are considered equipment or devices if the individual walks only with their help.

Does not walk means the patient does not usually walk. He may be helped to take a few steps from bed to chair or bathroom, but this alone does not constitute walking.
If the patient walks freely in the house but does not usually walk outside by himself, this classified as restricted walking (#2).

4. Travel

Travels freely means that the patient has no restrictions on pattern or destination.
Minor restriction/minor change means, for example, the patient's travel is limited or reduced, yet travels without help, drives care or takes bus without assistance within certain limits (may not travel as far). Interviewers ask about change since illness as another basis for distinguishing between codes 1 and 2.

Without help means that the patient goes outside the house and returns, without assistance from another person.

Help from another person or persons means that one or more persons helps the patient when he goes outside the house by:

- providing transportation
- providing physical support
- propelling wheelchair down (or up) ramp
- carrying the patient
- guarding, guiding, protecting, or supervising the patient (considered help if the patient gets outside the house only with this help)

Confined to home means that the patient does not **customarily** go outside the home.

5. Bathing

Without help of any kind means the patient receives no assistance or supervision from another person, nor from the use of special equipment or a device.

Minor restriction/minor change means another person helps the patient in:

Has hair dresser come in

Bringing the water and equipment to him. The patient then bathes himself completely or receives additional assistance, e.g., with his back, chest and abdomen, legs, feet.

Filling the tube with water, helping the patient in and out of the tube.

Towel drying

Observing, supervision, or teaching him to bathe himself.

Equipment and devices used include:

wig
shower chair or tube chair
grabrails, handle bars at sink, shower or tub
pedal or knee-controlled faucet
long-handled brush or sponge
mechanical lift into tube
electric razor

Is bathed (unable to participate) means the patient is completely bathed by another person or persons whether this be in bed, shower, or tube.
Bathing item includes generally hygiene habits of hair care and shaving. But bathing is primary, hair care is secondary.

6. Toilting

Without help of any kind means the patient receives no assistance or supervision from another person, nor does he use any equipment or device.

Minor restriction/minor change means, for example, the patient uses toilet with help of special equipment but does not require help of another person; toilet use may be slow and deliberate. Interviews ask about change since illness as another basis for distinguishing between codes 1 and 2. Pattern of elimination (both urination or bowel) may change as result of treatment or disease.

Help from another person means another person or persons helps the patient in:
getting to and from the toilet seat
adjusting clothes

transferring on and off the toilet seat
cleansing after elimination

Equipment and devices used include:
colostomy bag
raised toilet or raised toilet seat
handrails or grab bars
wheel chair, walker, or multiprong cane
transfer broad

II. Social Competence

7. Activities in the Home

Range of usual household role includes:

cooking	managing the household finances		laundry
garbage disposal	lawn care	shopping	running errands

Usual activity means what was customary for that person prior to illness

Modified activity means that **all** activities in the patient's role repertoire are maintained to some extent, e.g., cooking patterns change—freezes food instead of cooking every day.

Restricted activity means that some behaviors have completely dropped out of the patient's role repertoire (e.g., patient no longer cooks meals, does laundry, or runs errands).

8. Work-Type Activities

Usual activity means what was customary for that person prior to illness.
Work for retired person is what the person does with time as a retired person; e.g., second job, church activities, woodwork, volunteers.
Activities can be done alone or with other people.

9. Recreational and Social Activities

Activities includes:

going to movie	taking a walk	bowling
going on vacation	having friends over	
going out to dinner	church bingo	reading
attending musical or theatrical events		

Usual activity means what was customary for that person prior to illness.

Appendix D. Annotated Bibliography for Studies Using the Enforced Social Dependency Scale

This section presents an annotated bibliography of published studies that used the ESDS. The key findings of each study are included even though they may not be directly related to the ESDS.

1. **McCorkle, R., & Benoliel, J.Q. (1981).** *Cancer patient responses to psychosocial variables. Final Report of project supported by Grant No. NU00730*, DHHS, University of Washington.

Roles of the ESDS: to detect patients' psychosocial responses to chronic illness.

Purpose:

- Develop and test a battery of instruments intended to identify coping strategies of patients to adjust specific psychosocial problems associated with advanced cancer.
- Identify differences in physical-social responses, personal responses and coping responses of patients with two different advanced diseases.

Design:

A short-term longitudinal, exploratory design. Patients were interviewed twice at one and two months post-diagnosed.

Samples:

Sixty-one cancer patients and 52 myocardial infarction patients. The majority of patients were males, married, and Caucasian. The subjects' ages ranged from 32 to 81 with the mean age being 62 years for cancer subjects and 61 years for MI patients.

Measures:

ESDS, Symptom Distress Scale (SDS), Words describing Pain, Inventory of Current Concerns, Staff Support, Profile of Mood States (POMS), Personal Goals, Acknowledged Awareness scale, Eysenck Personality Inventory.

Findings:

- Cancer patients suffered from more physical symptom distress and pain and more mood disturbance than myocardial infarction patients.
- Except for physical distress and mood disturbance, cancer and heart attack patients did not differ significantly on concerns, social dependency, staff support, broad personality adjustment and acknowledged awareness at both one and two months post-diagnosed interviews.
- Both groups of patients reported fewer concerns and better mood at the second interview.

- Social dependency decreased significantly for MI patients between the two occasions.
- For both groups of patients at the two occasions, symptom distress produced greater social dependency, greater mood disturbance, and more concerns. Particularly for cancer patients, from 20 to 30% of the total variation in social dependency, mood disturbance, and concerns were accounted for by symptom distress alone.
- For both cancer and heart attack patients, social dependency was adequately accounted for by physical symptoms (including pain) alone.
- Social dependency was found to have a negative effect on the concerns of cancer patients at both occasions.
- Mood disturbance and concerns were affected by physical and psychosocial factors. Acknowledged awareness was determined mainly by psychosocial factors.

2. Young, K.J., & Longman, A.J. (1983). Quality of life and persons with melanoma: A pilot study. *Cancer Nursing, 20,* 219-225.

Roles of the ESDS: as an explanatory factor of quality of life.

Purpose:

Investigate variables associated with quality of life as perceived by persons diagnosed with melanoma.

Design:

Descriptive, correlational design.

Sample:

A convenience sample of 23 patients with melanoma. Fifty-two per cent of these subjects were male. The majority of subjects were married and living with their spouses. The range of age was from 29 to 70 years.

Measures:

Quality of Life Scale, SDS, ESDS, Behavior-Moral Scale.

Findings:

- Symptom distress was inversely associated with quality of life, such that as symptom distress increased, QOL decreased.
- Social dependency was inversely associated with quality of life. Patients with higher social dependency rated poorer quality of life.
- Behavior-moral and quality of life were positively associated.
- Significant life change items were negatively associated with quality of life.

3. Donaldson, G., McCorkle, G., Georgiadou, F. & Benoliel, J. (1986). Distress, dependency, and threat in newly diagnosed cancer and heart disease patients. *Multivariate Behavioral Research, 21*, 267-298.

Roles of the ESDS: as one of the outcome measures of life-threatening illness.

Purpose:

- Compare the effects of life-threatening illness on symptom distress, social dependency, concerns, mood, personality, and evaluation of problem management of patients with either lung cancer or myocardial infarction.
- Test a model of threat assimilation in these two groups of patients by examining individual differences.

Design:

A short-term longitudinal study design was used to interview subjects at one and two months post lung cancer diagnosis or heart attack.

Sample:

Fifty-six patients with newly diagnosed lung cancer and 65 patients with a recent myocardial infarction. Both samples were predominantly male, white, and from middle-to-upper-class socioeconomic backgrounds. All subjects but two myocardial infarction patients were over 40 years old. There were no significant differences on demographic characteristics between the two samples.

Measures:

SDS, ESDS, Inventory of Current Concerns, POMS, Self Evaluation Scale, Personality Factor Questionnaire, Eysenek Personality Questionnaire.

Findings:

- Lung cancer patients had more symptom distress and concerns, and evaluated themselves more harshly than heart attack patients at both time points.
- Although symptom distress remained unchanged between time one and time two, both lung cancer and myocardial infarction patients reported significant improvement in mood and concerns by the second month post-diagnosed or post heart attack, thus lending support for the threat assimilation model.
- There was a significant disease and occasion interaction effect for ESDS. Myocardial infarction patients were notably less socially dependent at the second occasion while cancer patients are essentially unchanged.
- Structural equation models of individual differences suggested that, though the two groups were characterized by mean differences, the causal processes determining individual responses to the trauma of life-threatening illness were similar in both groups.
- Symptom distress was the most pervasive and powerful influence on emotional-cognitive distress, social dependency, and self-evaluation. Symptom distress directly affected emotional-cognitive distress and self-evaluation at the second occasion and indirectly influenced self-evaluation at the first occasion. Emotional-cognitive distress

mediated the effect of symptom distress on self-evaluation at occasion one but symptom distress determined self-evaluation at the second occasion.

- Emotional-cognitive distress and self-evaluation were not affected by social dependency at either occasion. Although patients with high scores on the ESDS also tended to be high in emotional-cognitive distress and be low in self-evaluation, such correlations were mainly attributable to the common influence of symptom distress.

4. Kukull, W.A., McCorkle, R., & Driver, M. (1986). Symptom distress, psychosocial variables and survival from lung cancer. *Journal of Psychosocial Oncology, 4*, 91-104.

Roles of the ESDS: as one of the potential predictors of survival from lung cancer.

Purpose:

Examine the relative importance of symptom distress and psychosocial variables in predicting survival from lung cancer.

Design:

Longitudinal study design. Patients were followed for three and one-half years after the initial diagnosis and treatment.

Sample:

Fifty-three patients with inoperable lung cancer treated with radiation therapy. The mean age of the subjects was 62 years. Most of the subjects were Caucasian and male.

Measures:

SDS, McGill Pain Questionnaire, Inventory of Current Concerns, ESDS, POMS, Acknowledged Awareness, Personality Factor Questionnaire, Eysenck Personality Inventory.

Findings:

- The patients' post-diagnosis symptom distress score was the most important predictor of survival after adjusting for age, functional status, and personality traits.
- Enforced social dependence either individually or in combination with age, sex, personality traits did not add significantly to the model after symptom distress was included.

5. Degner, L.F., Henteleff, P.D., & Ringer, C. (1987). The relationship between theory and measurement in evaluations of palliative care services. *Journal of Palliative Care,* 3(2), 8-13.

Roles of the ESDS: as one of the outcome measurements of palliative care services.

Purpose:

Test a method for measuring the effectiveness of an established palliative care service.

Design:

Pre-test-Post test design. The first testing occurred with 48 hours of admission to the palliative care unit and the second testing occurred seven days after the first test.

Sample:

Twenty-nine terminal cancer patients who were admitted to the palliative care unit for the first time. There was an approximately equal distribution of males and females. The patients' age ranged from 33 to 89 years with a mean of 65.5 years.

Measures:

SDS, ESDS, Quality of Life Index.

Findings:

- The mean the SDS scores of subjects decreased from 33.8 at the time of admission to 25.7 at seven days after the first test. Improvement of symptoms was primarily noted in the frequency and intensity of pain and bowel patterns.
- Mean scores of the ESDS increased from 37.2 at the time of admission to 43.3 at seven days after the first test.
- There was a significant and negative correlation between the nurses scores on Quality of Life Index and the patients' ESDS scores (r= -0.49, P= 0.01).

6. Young Graham, K., & Longman, A.J. (1987). Quality of life and persons with melanoma: Preliminary model testing. *Cancer Nursing, 10,* 338-346.

Roles of the ESDS: as one of the determinants of quality of life.

Purpose:

Investigate quality of life of patients with melanoma and the relationships between quality of life and symptom distress, social dependency, behavior-moral, and life change.

Design:

Descriptive, correlational, cross-sectional design.

Sample:

There were 32 men and 28 women, aged from 20 to 83 years, with a mean of 49.6 years. The majority of patients were married and working outside the home.

Measures:

Quality of Life Scale, SDS, ESDS, Behavior-Moral Scale, Life Change Scale.

Findings:

- Symptom distress was inversely associated with quality of life (r=-0.34).
- Social dependency was inversely associated with quality of life (r=-0.28).
- Behavior-moral was positively associated with quality of life (r=0.38).
- Amount of life change and direction of life change as measured by Life Change Scale

was not correlated with quality of life.

- Social dependency was significantly associated with symptom distress (r=0.31), amount of life change (r=0.39), and direction of life change (r=0.42).
- Social dependency was negatively related to behavior-moral (r=-0.34).
- Analyses from stepwise multiple regression revealed that only 10% of the variance in quality of life could be explained by identified variables, with no statistically significant contributions from social dependency or the life change variables.

7. McCorkle, R., Benoliel, J.Q., Donaldson, G., Georgiadou, F., Moinpour, C. & Goodell, B. (1989). A randomized clinical trial of home nursing care for lung cancer patients. *Cancer, 64*, 1375-1382.

Roles of the ESDS: as one of the outcome measurements of the effects of home nursing care for lung cancer patients.

Purpose:

Assess the effects of home nursing care for patients with progressive lung cancer.

Design:

Longitudinal, randomized experimental design. Patients were entered into the study 2 months after diagnosis and followed for 6 months. Patients were interviewed at 6-week intervals across five occasions.

Sample:

One hundred sixty-six patients with advanced lung cancer were assigned to either an oncology home care group, a standard home care group, or an office care group. Of the 166 patients, 105 were men and 61 were women. Most of the subjects were white, married, and older than 60 years old.

Measures:

SDS, McGill-Melzack Pain Questionnaire, Inventory of Current Concerns, POMS, ESDS, General Health Rating Index.

Findings:

- The three groups did not differ significantly with respect to pain, mood disturbance, and concerns.
- There were significant differences in symptom distress, enforced social dependency, and health perceptions among the three groups. The two home nursing care groups had less distress and greater independence 6 weeks longer than the office care group. In addition, the two home nursing care groups steadily reported worse health perceptions over time.
- Although differences were not significant, the oncology home care group had fewer hospitalizations and lower total length of hospital stays than the other two groups.

8. Edwards, M.E.J. (1990). *Prediction of delayed or interrupted recovery among elective surgery patients: A nursing perspective.* Ph.D Dissertation. University of Texas at Austin.

Roles of the ESDS: as one of outcome measurements of recovery from elective surgery.

Purpose: to determine the predictive value of specific psychosocial and demographic characteristics in identifying patients who would experience an interrupted or delayed recovery from elective surgery.

Design:

Descriptive correlational design.

Sample:

A total of 117 patients, predominantly female and married with a mean age of 46 years. Abdominal hysterectomy was the most frequent surgical procedure.

Measures:

Self Evaluated Health, The Family APGAR, Health Perceptions Questionnaire (HPQ), Perceived Stress Scale (PSS), Edwards Recovery Scale, and ESDS.

Findings:

- Females reported lower Edwards Recovery Scale scores but also reported lower ESDS scores (lower independent levels) than the male subjects.
- The subjects' perceptions of stress were negatively correlated with the Edwards Recovery Scale from the first and second interview scores and with the ESDS scores from the second interview.
- Comparison of the influence of independent variables on outcome measures in three multivariate analyses were displayed as following:

Predictive variables for recovery from elective surgeries

	Multiple Regression	Discriminant Analysis	Logistic Regression
Outcomes	Predictor Variables		
Recovery Scale	Surgery HPQ26 Age 22.8% variance	Surgery PSS Age HPQ26 Marital 80.6% correctly classified	Surgery PSS HPQ26 75.7% correctly classified
ESDS	Surgery Gender HPQ26 26.7% variance	Gender HPQ26 Surgery 83% correctly classified	Gender HPQ26 83.3% correctly classified
Total Recovery	Surgery Gender HPQ26 Marital 36.9% variance	Surgery Gender PSS HPQ26 Marital 85% correctly classified	Marital Gender Surgery HPQ26 PSS 81% correctly classified

9. Naylor, M.D. (1990). Comprehensive discharge planning for hospitalized elderly: A pilot study. *Nursing Research, 39*, 156-161.

Roles of the ESDS: as a screening tool for determining the compatibility of basic characteristics between experimental and control group.

Purpose: to examine the effects of a comprehensive discharge planning protocol implemented by a gerontological nurse specialist as compared to the hospital's general discharge planning procedure.

Design:

Longitudinal, randomized clinical trial. Patients were interviewed at 2-, 4-, and 12-weeks post-discharge.

Sample:

A total of 40 hospitalized cardiac medical and surgical patients, 70 years or older.

Measures:

Short Portable Mental Status Questionnaire, ESDS.

Findings:

- There were no statistically significant differences between the two groups in mental status, personal competence, or social competence measured within 24 hours after hospital admission.
- There were no statistically significant differences between groups in the length of initial patient hospitalization or in the rates of post-hospital infections.
- A statistically higher number of patients who were rehospitalized during the study period were found in the control group.
- There was no statistically significant difference in costs of initial hospitalization.

10. Willard, G.A. (1990). *Development of an instrument to measure the functional status of hospitalized patients.* Ph.D Dissertation. University of Texas at Austin.

Roles of the ESDS: as a gold standard measure of concurrent construct validity of the Functional Status Instrument.

Purpose:

- Develop a valid Functional Status Instrument that reliably measures the functional status of patients when used by registered nurses.
- Test psychometric properties of the Functional Status Instrument.

Design:

Three-phase instrument development study.

Sample:

A total of 38 patients admitted for a total hip or knee replacement procedures were assessed for functional status preoperatively and postoperatively days one, five, and ten. The mean age of subjects was 63 years and 68% of the subjects were male.

Measures:

Functional Status Instrument (FSI), ESDS, studied hospital standardized subject dependency rating scale (Acuity).

Findings:

- The FSI content validity was established by a panel of nurse experts at Content Validity Index (CVI) =0.86.
- Concurrent validity was established by correlations of the FSI and the ESDS and ranged from 0.59 to 0.98. Concurrent validity was also established by correlating the FSI scores with patients' acuity levels. Correlations of the FSI scores and patients' acuity levels ranged from 0.25 to 0.50.
- Predictive validity was established by correlating the FSI scores with patients' length of stay in the hospital. The FSI scores correlated significantly ($p<0.05$) with patients' length of stay, ranging from -0.28 to-0.32.
- Internal consistency of the FSI estimated by Cronbach's Alpha ranged from 0.84 to 0.94.

- The FSI is sensitive to functional status changes when measured preoperatively, and postoperatively day 1, 5, and 10 (p=0.05).
- The correlation between the scores on the ESDS and acuity levels was strong, positive, and significant (r=0.74, p=0.01).
- The correlation between the scores on the ESDS and length of stay was strong, positive, and significant (r=0.75, p=0.016).

11. Cochrane, B.B. (1992). *Women's integration of the myocardial infarction experience: Reclaiming independence after a heart attack.* Ph.D Dissertation. University of Washington.

Roles of the ESDS: as an outcome measure of recovery from heart attack to describe patterns of change in functional activity over the first three months after acute myocardial infarction.

Purpose:
- Develop a grounded theory to describe the process whereby women integrate their myocardial infarction experiences.
- Describe patterns of change in functional activity, emotional distress, and coherence.

Design:

Longitudinal, exploratory, and triangular study. Data were collected at three occasions: (1) within 1 week of hospital admission; (2) within 1 to 2 weeks after discharge; and (3) approximately 8 to 10 weeks after discharge.

Sample:

Sixteen women, age 50 to 86 years (mean age 69.1 years).

Measures:

POMS, Coherence Scale, ESDS.

Findings:
- Core phenomenon for women to integrate their myocardial infarction experiences was their reclaiming independence after a heart attack. The causal conditions for this experience were becoming alert to the need for help and becoming a patient. Contexts within which this process evolved were one's independence prior to the MI and the severity of the MI. Strategies included enduring the confinement and constraints, affirming one's reality, and negotiating the recovery. The care and vigilance of health care providers, discrepancies occurring between expectations and experience, and one's relationships with others mediated the experience. The outcomes of reclaiming independence were achieving balance between dependence and independence and regaining a normal life.
- The ESDS scores showed a significant consistent pattern of decreased dependency and increased functional activity over time (p<0.002).
- During their first two weeks of discharge from the hospital, women who lived alone

prior to their MI showed increased depression (p<0.03) and a decreased sense of coherence (p<0.01) compared to partnered women.

- Nonpartnered women had higher ESDS scores in the hospital compared to partnered women (P<0.04).
- The ESDS scores were significantly (P<0.01) correlated with Coherence Scale scores, POMS, and length of stay.

12. Cowan, M.J., Graham, K.Y., & Cochrane, B.L. (1992). Comparison of a theory of quality of life between myocardial infarction and malignant melanoma: A pilot study. *Progress in Cardiovasuclar Nursing, 7*, 18-28.

Roles of the ESDS: as one of the explanatory variables of perceived quality of life.

Purpose:

Describe the relationships among manifest symptom distress, functional alterations, cognitive adaptation and quality of life defined by Graham-Cowan model for perceived quality of life and compare the results between patients with myocardial infarction and malignant melanoma.

Design:

Cross-sectional, descriptive, and comparative study.

Sample:

Twenty-seven patients with myocardial infarction and 30 patients with malignant melanoma. All patients had been diagnosed within one year of the interview. The majority of subjects were male, Caucasian, married, and middle to upper socioeconomic status. Age range for the subjects was 31 to 70 years with a mean age of 53 years.

Measures:

Quality of Life Index, Graham Global Well-Being Scale, Current Quality of Life Scale, Satisfaction with Current Quality of Life scale, Cognitive Adaptation, Coherence Scale, Rosenberg Self-Esteem Scale, Symptoms of Stress Inventory, SDS, Psychological Distress Subscale, Psychosocial Adjustment to Illness Scale, Functional Status Questionnaire, ESDS.

Findings:

- Manifest symptom distress was directly related to functional alterations, and inversely related to cognitive adaptation and perceived quality of life.
- Functional alterations were inversely related to cognitive adaptation and perceived quality of life.
- Cognitive adaptation was directly related to perceived quality of life.
- There were no significant differences between the myocardial infarction and malignant melanoma subjects for all of the aforementioned relationships.
- The ESDS was positively correlated with manifest symptom distress and negatively related to perceived quality of life and cognitive adaptation.

- The persons with the higher severity of disease had significantly higher scores on the ESDS (p=0.009).

13. DesRosier, M.B., Catanzar, M., & Piller, J. (1992). Living with chronic illness: Social support and the well spouse perspective. *Rehabilitation Nursing, 17*, 87-91.

Roles of the ESDS: to assess and describe the demands for physical care of multiple sclerosis on the caregivers.

Purpose:

Describe the experience of wives of husbands homebound with multiple sclerosis.

Design:

Naturalistic inquiry, using focus groups for data collection.

Sample:

Nine women with a mean age of 49.8 years (SD=6.3) and an average of 21 years (SD=10.2) of marriage.

Measures:

Personal competence scale of ESDS.

Findings:

- The husbands of the women in the groups had scores of personal competence subscale of ESDS ranging from 6 to 27 with a mean score of 21.1 (SD=9).
- Study participants described themselves as being restricted to the home by caregiving requirements and dependent on their disabled husband for support.
- Never having time away from the husband strained the marital relationship and threatened the supportive nature of the relationship.
- Creating space for themselves and having personal time away from their husband helped them avoid or reduce negative outcomes of the social support received from their husband.

14. Long, K.A., & Weinert, C. (1992). Descriptions and perceptions of health among rural and urban adults with multiple sclerosis. *Research in Nursing & Health, 15*, 335-342.

Roles of the ESDS: personal competence subscale of the ESDS to measure the health perceptions of patients with multiple sclerosis.

Purpose:

Describe and compare the health descriptions and perceptions of adults with multiple sclerosis living in rural and urban areas.

Design:

Secondary analyses of a national study of the effects of long-term illness on individuals and their families.

Sample:

361 patients with multiple sclerosis with a mean age of 44.8 years (SD=7.7) and a mean of 11.1 (SD=7.0) years of illness. The majority of these patients were white and women

Measures:

General Health Rating Scale, Center for Epidemiologic Studies—Depression Scale (CES-D), Personal competence subscale of ESDS, psychosocial dimension of the Sickness Impact Profile, Personal Resource Questionnaire-Part 2.

Findings:

- Respondents rated their overall general health as poorer than that reported for the general population.
- The mean score for the study sample on the CES-D was well above the published norm and slightly below the score used as an indicator of clinical depression.
- Respondents had only a few limitations in performing the activities of daily living as measured by the personal competence subscale of the ESDS.
- The level of psychosocial functioning and perceived social support for study samples did not significantly differ from those of persons living with other chronic illnesses.
- The health perceptions and descriptions of this chronically ill population were not significantly affected by their place of residence.

15. Taylor, E.J. (1992). *The search for meaning among persons living with recurrent cance.* Ph.D Dissertation. University of Pennsylvania.

Roles of the ESDS: as one of the predictors of searching for meaning and sense of meaning.

Purpose:

- Describe the prevalence and context of the phenomenon of search for meaning among persons living with recurrent cancer.
- Investigate patients' perceptions of the process and outcomes of the search for meaning.
- Identify factors associated with the search for meaning and finding meaning.

Design:

Exploratory, descriptive, and correlational study.

Sample:

Seventy-four persons diagnosed with recurrent cancer. Sixty per cent of subjects were female. Their ages ranged from 23 to 81 years with an average age of 54 years. The majority of subjects were Caucasian, married, and lived with someone.

Measures:

Purpose in Life Test (PIL), SDS, ESDS, Psychosocial Adjustment to Illness Scale (PAIS-SR), Search for Meaning Survey (SMS).

Findings:

- Slightly over half (56.9%) of those interviewed reported searching for meaning.
- Seventy-six percent and 64% of subjects reported that, the first timing for their searching for meaning was when they were diagnosed and at recurrence, respectively.
- Significant and inverse correlations were observed between the sense of meaning in life and symptom distress, social dependency, and length of time since diagnosis of recurrence.
- Adjustment to illness was positively correlated with sense of meaning.
- Persons who reported that they had found at least some meaning had higher PIL scores than subjects who responded that they had not found meaning.
- There was no significant difference in sense of meaning between those who searched and those who did not search, yet those who searched had poorer adjustment to illness.
- The sense of meaning, the search for meaning, and the finding of meaning were not significantly associated with most demographic variables.
- Factors related to thoughts of meaning included: symptom distress, treatment-related activity, family relations, thoughts of death, and religiosity.
- The outcomes of the search for meaning included causal attributions, construed good, and perceptions regarding ways of the universe.

16. O'Hare, P.A., Malone, D., Lusk, E., & McCorkle, R. (1993). Unmet needs of black patients with cancer post-hospitalization: A descriptive study. *Oncology Nursing Forum, 20*, 659-664.

Roles of the ESDS: to describe the functional dependency of study subjects and to compare with those of patients from another study which was conducted in Seattle.

Purpose:

Describe the self-reported post-hospitalization unmet needs of black patients with cancer and identify patients at greater risk for unmet needs.

Design:

Secondary analysis of a larger longitudinal study. Data from the first interviews which occurred within 30 days of discharge from hospital, were analyzed.

Sample:

Sixty-three black patients with solid tumors. Most of the patients were older than 50 years old, low income, unmarried, poorly educated, with advanced cancer, disabled, or retired, no private insurance coverage, and urban dwelling.

Measures:

ESDS, Unmet Needs Checklist, SDS, audits of home health care agency referral form.

Findings:

- The most common unmet needs identified in this study were eating, walking, bathing and personal care.
- Patients who lived alone reported more unmet personal needs than those who lived with others.
- Women who were elderly, alone, poor and chronically ill were more likely to have unmet needs and higher levels of symptom distress.
- The overall mean social dependency score of subjects in this study was 29.3, which is significantly greater than those of patients from Seattle with lung cancer (Mean=25.0 and SD=6.2; $p<0.01$).

17. Sarna, L., Lindsey, A.M., Hannah, D., Brecht, M.L., & McCorkle, R. (1993). Nutritional intake, weight change, symptom distress, and functional status over time in adults with lung cancer. *Oncology Nursing Forum, 20*, 481-489.

Roles of the ESDS: as one of the explanatory factors of nutritional intake for adults with lung cancer.

Purpose:

Describe the relationship of nutritional intake to weight change, symptom distress, and functional status over a six-month period. Examine the relationships among (1) weight change, food intake, and functional status, (2) symptom distress, hunger, appetite, nausea, functional status, and food intake, and (3) differences in food intake and weight changes and among demographic and clinical variables.

Design:

Secondary analysis of a larger longitudinal experimental study that assessed the effects of home nursing care on the psychosocial well-being of patients with progressive lung cancer. Patients were interviewed every six weeks for six months.

Sample:

Twenty-eight patients who were newly diagnosed with lung cancer. Most of the subjects were male, Caucasian, with a mean age of 62 years and had stage III non-small cell lung cancer and were receiving treatment.

Measures:

Scale to measure weight in pounds, a self-recorded diet intake form, Hunger Linear Analog Scale, SDS, ESDS.

Findings:

- Average weight change and nutritional intake showed little variation over time, but the ranges were large.

- Lower intake of kilocalories was significantly and moderately related to subsequent decrease in functional status.
- At study entry, subjects who lost 10 lbs, or more, as well as those who lost 10% or more of body weight, showed significantly greater functional impairment than those who lost less than 10 lbs, or less than 10% of body weight.
- Weight change was not directly related to kilocalorie intake.
- Symptom distress and symptoms of hunger, nausea, and appetite disturbance showed subtle fluctuations over the six-month period and had inconsistent relationships with food intake over time.
- Percentage of weight loss over time was greater in subjects younger than 65 years of age, in those with small cell lung cancer, and in those who received chemotherapy.

18. Taylor, E.J. (1993). Factors associated with meaning in life among people with recurrent cancer. *Oncology Nursing Forum, 20*, 1399-1407.

Roles of the ESDS: as a predictor of sense of meaning in patients with recurrent cancer.

Purpose:

Determine what factors were associated with the sense of meaning in life among patients with recurrent cancer.

Design:

Correlational, cross-sectional study.

Sample:

Seventy-four patients with a diagnosis of recurrent cancer of various types. Mean age of the study subjects was 54 years. The majority of subjects were white, female, married and had a high socioeconomic status.

Measures:

Purpose in Life Test, Psychosocial Adjustment to Illness Scale, SDS, ESDS, Search for Meaning Surveys.

Findings:

- Scores of Purpose in Life Test were significantly associated with Psychosocial Adjustment to Illness Scale, the SDS, and the ESDS scores in a negative and low-moderate degree.
- Scores of Purpose in Life Test were inversely correlated with the length of time since diagnosis of recurrence.
- Married and middle-aged adults had significantly higher scores of Purpose in Life Test.
- The ESDS was positively correlated with Psychosocial Adjustment to Illness Scale and the SDS score.
- Adjustment and marital status were the best predictors of sense of meaning, accounting for 33.5% of its variance.
- Symptom distress and dependency showed little effect on sense of meaning once

adjustment was entered into the equation.

19. Yost, L.S., McCorkle, R., Buhler-Wilkerson, K., Schultz, D., & Lusk, E. (1993). Determinants of subsequent home health care nursing service use by hospitalized patients with cancer. *Cancer, 72*, 3304-3312.

Roles of the ESDS: as one of the predictors of home health care nursing service utilization by hospitalized cancer patients after discharge.

Purpose:

Examine the extent to which specific patient characteristics and length of hospital stay were capable of independently explaining the use of home health care nursing services by hospitalized patients with cancer after discharge from hospital.

Design:

Secondary analysis of a larger descriptive study aimed at identifying the home health care needs of patients with cancer. Interviews were conducted at discharge from the hospital and at three and six months post discharge.

Sample:

Eighty-seven patients with cancer who received home health care after hospitalization and 43 patients who did not receive such services. Most of the subjects were older than 50 years, married, white, metastases present and had health insurance.

Measures:

SDS, ESDS, CES-D, Risk Index, Health Perceptions Questionnaire.

Findings:

- Age, length of hospital stay, and level of symptom distress were significant determinants for home health care use in a forward step-wise logistic regression analysis. Subjects older than 50 years of age, hospitalized for more than 7 days, and those who experienced moderate to high levels of symptom distress were more likely to receive home health care services.
- ESDS demonstrated a significant association with home health care use in a univariate analysis (p=0.011) but did not enter the final model as an independent explanatory variable. This occurrence may be related to the association of ESDS with the variable of symptom distress (p=0.003) which entered the final model.

20. McCorkle, R., Jepson, C., Malone, D., Lusk, E., Braitman, L., Buhler-Wilkerson, K., & Daly, J. (1994). The impact of posthospital home care on patients with cancer. *Research in Nursing & Health, 17*, 243-251.

Roles of the ESDS: as one of the outcome measurements of home care service

Purpose:

Evaluate the impact of home care services on the symptom distress, mental health, enforced social dependency, and health perceptions of cancer patients following an acute care hospital stay.

Design:

Secondary analysis of a larger longitudinal study aimed at describing the post-hospitalization needs of cancer patients and the adequacy with which those needs were met by the home care services provided to them. Interviews were conducted at discharge from the hospital and at three and six months post discharge.

Sample:

Sixty patients with solid tumors. Of these patients, 49 patients received home care services and 11 did not receive home care services posthospitalization. Most of the subjects were female, white, older than 50 years of age, and had at least a high school education.

Measures:

SDS, ESDS, Health Perceptions Questionnaire, Mental Health Status Inventory.

Findings:

- Home care patients had significantly greater symptom distress at baseline than the no home care patients.
- Home care patients had significant improvements in mental health and dependency over time as compared with no the home care group.
- After controlling for the baseline differences in the psychosocial measures, the home care group had significantly higher mental health status at three months after discharge than the no home care group. A nonsignificant trend in the same direction was observed for dependency (P=0.08).

21. Sarna, L., Lindsey, A.M., Hannah, D., Brecht, M.L., & McCorkle, R. (1994). Weight change and lung cancer: Relationships with symptom distress, functional status, and smoking. *Research in Nursing & Health, 17*, 371-379.

Roles of the ESDS: as one of the explanatory factors of weight change for adults with lung cancer.

Purpose:

- Describe the pattern of weight change in adults with progressive lung cancer over a six month period.
- Investigate the relationships of symptom distress, functional status and smoking status with weight change over time
- Explore differences in patterns of weight change by demographic and clinical subgroups.

Design:

Secondary analysis of a larger longitudinal clinical trial. Patients were interviewed every six weeks for six months.

Sample:

Sixty patients with lung cancer. The average age of the study participants was 62.3 years. The majority of the subjects were male, Caucasian, lived with others, had non-small cell lung cancers, and received some form of treatment.

Measures:

Scale to measure weight in pounds, SDS, ESDS, self-report of smoking behavior.

Findings:

- Changes from pre-illness body weight ranged from a 31% loss to a 32% gain.
- Almost half of the sample (46.9%) lost weight over six months, 15.6% had no change, and 37.5% experienced a weight gain.
- Weight loss was significantly correlated with subsequent increased symptom distress.
- Pre-illness weight loss was moderately correlated with subsequent decreased functional status ($p<0.001$).
- Chemotherapy and smoking predicted weight loss from Time 1 to 5, explaining 28% of the variance.

22. Weinert, C., & Catanzaro, M. (1994). Challenging assumptions about multiple sclerosis. *Rehabilitation Nursing Research, 3*(4), 122-129.

Roles of the ESDS: Use of personal competency scale of ESDS to present the degree of physical disability of multiple sclerosis and to test its effects on family cohesion and satisfaction.

Purpose:

- Describe the Family Health Study
- Compare the scale scores of the study participants with multiple sclerosis and their spouses with published scores
- Examine the assumption that health-related variables negatively affect family function

Design:

Combination of a longitudinal single-cohort panel design and a multiple embedded case study design. The focus of this study was on cross-sectional survey data collected from the longitudinal cohort panel.

Sample:

Six hundred and four patients with multiple sclerosis. The average age of the subjects was 45.5 years. The majority of participants were female, white, middle class, and had been married an average of 19.2 years.

Measures:

Personal competence scale of ESDS, Dimension II of the Sickness Impact Profile, CES-D, Perceived Stress Scale, Dyadic Adjustment Scale, Family APGAR, FACES III.

Findings:

- Psychosocial disability level as measured by SIP of the participants was within the range reported for others living with chronic illness.
- The mean score on the personal competency scale of the ESDS was 12.81, indicating a low to moderate level of physical disability.
- The mean score on the CES-D was 15.56, well above that reported for age-comparable groups.
- These study families scored lower on measures of (a) family cohesion and adaptability and (b) dyadic consensus and satisfaction than families reported in the literature.
- Disease characteristics, such as length of illness and level of disability, had little or no influence on family cohesion and dyadic consensus and satisfaction.
- Modifiable factors, such as depression, were more likely to be responsible for family dysfunction.

23. Barsevick, A., Pasacreta, J., & Orsi, A. (1995). Psychological distress and functional dependency in colorectal cancer patients. *Cancer Practice, 3*, 105-110.

Roles of the ESDS: as one of the outcome measures of the effects of colorectal cancer diagnosis and treatment.

Purpose:

- Describe the nature and degree of psychological distress that persons experience after being diagnosed with colorectal cancer.
- Examine the biopsychosocial factors that impact on functional dependency during the first three months of treatment.

Design:

Longitudinal, descriptive study. Interviews were conducted before surgery as well as 1 and 3 months after surgery.

Sample:

Sixty-six colorectal cancer receiving surgery treatment. The mean age was 64 years. Participants were primarily male, married, white, and had at least a high school education.

Measures:

Bipolar Profile of Mood States, Beck Depression Inventory, ESDS.

Findings:

- Overall, levels of psychological distress, including negative mood and depressive symptoms, were quite low throughout the 3-month study.
- Beck Depression Inventory scores changed significantly with time ($P<0.001$) but Profile

of mood state scores did not change.

- Both cognitive-affective items and somatic-performance items contributed to the overall depressive symptom score.
- Preoperative and postoperative depressive symptoms as well as negative moods were correlated with functional dependency at the 3-month period.
- Having an ostomy, depressive symptoms and additional treatment were predictors of functional dependency after surgery.

24. Robinson, M.K. (1995). *Determinants of functional status in chronically ill adults*. Ph.D Dissertation. University of Alabama at Birmingham.

Roles of the ESDS: as the outcome measure of chronic illnesses.

Purpose:

- Examine the relationships among selected basic conditioning factors, self-care agency, and functional status in chronically ill adults.
- Determine the best predictors of self-care agency and functional status in chronically ill adults.

Design:

Descriptive, correlational study.

Sample:

A convenience sample of 90 chronically ill adults with three medical diagnoses (DM, essential hypertension, and chronic obstructive pulmonary disease) participated in this study. Ages ranged from 28 to 81 years with a mean of 59.7 years. The majority of the sample were male.

Measures:

The Denyes Self-Care Agency Instrument, ESDS.

Findings:

- A statistically significant linear relationship exists between educational level and self-care agency.
- The best predictor of self-care agency was educational level, which accounted for 9% of the variance. Gender, health state, and age didn't achieve significance in the final regression model.
- Health state was significantly correlated with functional status for the health problems of DM and COPD.
- Gender and health state provided the best combination of predictors for functional status. These variables accounted for 14% of the variance in functional status.
- Self-care agency was not related to functional status.

25. Jepson, C., Schultz, D., Lusk, E., & McCorkle, R. (1997). Enforced social dependency and its relationship to cancer survival. *Cancer Practice, 5*, 155-161.

Roles of the ESDS: as one of the potential predictors of cancer survival in a group of solid tumor patients.

Purpose:

Examine relationships between survival time and enforced social dependency in a group of cancer patients.

Design:

Secondary analysis of data from a larger longitudinal study designed to describe the post-hospitalization needs of patients with cancer with complex nursing problems and the adequacy with which those needs were met by the home care they received. Data used in this analysis are from the first interview, which took place before the patient's discharge from the hospital. Patients were followed 2 to 4 years later to ascertain survival status and for those who had died, date of death was recorded.

Sample:

One hundred and forty one patients with solid tumors. Most of the patients were male, married, white, and received some form of treatment and home care services.

Measures:

SDS, ESDS, Health Perceptions Questionnaire, CES-D.

Findings:

- From the univariate analyses, significant associations with survival were found for all psychosocial variables. High levels of symptom distress, enforced personal and social dependency, depression, and poor health perceptions were associated with shorter survival.
- Patients who were with no metastases, who received surgical treatment and those who did not receive chemotherapy had longer survival than other patients.
- Only enforced personal and social dependency were found to contribute significantly to the model of survival time.

26. Pasacreta, J.V. (1997). Depressive phenomena, physical symptom distress, and functional status among women with breast cancer. *Nursing Research, 46*, 214-221.

Roles of the ESDS: as one of the outcome measurements of the effects of depressive symptoms and symptom distress.

Purpose:

- Describe the nature and scope of depressive syndromes, depressive symptoms, and physical symptom distress in women 3 to 7 months after initial breast cancer diagnosis.
- Examine the relationship of depressive symptoms and physical symptom distress to functional status outcomes.

Design:
Cross-sectional telephone interview.

Sample:
Seventy-nine women who had been diagnosed and treated surgically for breast cancer within the previous 3 to 7 months. The age of the subjects ranged from 25 to 85 years with a mean age of 54.9 years. The majority of the sample was White, married and well educated.

Measures:
Diagnostic Interview Schedule, CES-D, SDS, ESDS, Cognitive Capacity Screening Test.

Findings:
- Nine percent of the sample had depressive disorder, and 24% had elevated depressive symptoms.
- Women with elevated depressive symptoms had more physical symptom distress ($p<0.001$) and more impaired functioning ($p<0.0001$) than subjects with depressive disorders and those without depression.
- Symptom distress and depressive symptoms accounted for 35% of the variance in functional status.
- Subjects who received chemotherapy before or after surgery were not more depressed but had significantly more symptom distress and poorer functional status than subjects who did not receive chemotherapy.

27. York, R., Brown, L.P., Samuels, P., Finkler, S.A., Jacobsen, B., Persely, C.A., Swank, A., & Robbins, D. (1997). A randomized trial of early discharge and nurse specialist transitional follow-up care of high-risk childbearing women. *Nursing Research, 46,* 254-261.

Roles of the ESDS: as one of the outcome measures in an intervention study of early discharge of high-risk childbearing women by using a model of clinical nurse specialist transitional follow-up care.

Purpose:
Evaluate the impact of a model of transitional care provided by perinatal nurse specialists in a group of women diagnosed with diabetes or hypertension during pregnancy on maternal outcomes, infant outcomes, and costs of care.

Design:
Randomized clinical trial.

Sample:
Ninety-six women who were diagnosed with either diabetes or with hypertension and

93 infants. Mean age for the control group subjects was 27 years, and 28 years for intervention group.

Measures:
ESDS, LaMonica-Oberst Patient Satisfaction Scale

Findings:
- There was no difference in functional status between the intervention and control groups at 2, 4, and 8 weeks postpartum. For both groups, personal and social functioning improved over time.
- There was no difference in satisfaction with care between the intervention and control groups.
- During pregnancy, the intervention group had significantly fewer re-hospitalizations than the control group.
- For infants of diabetic women enrolled in the study during their pregnancy, low birth weight (≤ 2,500 g) was three times more prevalent in the control group than in the intervention group.
- The postpartum hospital charges for the intervention group were also significantly less than for the control group. The mean total hospital charges for the intervention group were 44% less than for the control group.
- The mean cost of the clinical specialist follow-up care was 2% of the total hospital charges for the control group.
- A net savings of $ 13, 327 was realized for each mother-infant dyad discharged early from the hospital.

28. McCorkle, R., Hughes, L., Robinson, L., Levine, B., & Nuamah, I. (1998). Nursing interventions for newly diagnosed older cancer patients facing terminal illness. *Journal of Palliative Care, 14*(3), 39-45.

Roles of the ESDS: as one of the outcome measures of the effects of home nursing care provided to cancer patients who died within the study period after receiving the episode of home care.

Purpose:
- Describe the demographic and clinical characteristics, self-reported levels of symptom distress, functional status, and depression of patients who died at 3 and 6 months post-hospitalization.
- Describe types of nursing interventions provided to the subjects during the episode of home care.
- Explore the relationships between nursing interventions and patients' clinical outcomes (symptom distress, functional status, and depression).

Design:
Secondary analysis of a larger federally funded randomized clinical trial conducted to examine the effects of home nursing care on quality of life outcomes for post-surgical

cancer patients over 60 years of age.

Sample:

Thirty-seven cancer patients who died after receiving the complete home nursing intervention. Most of the subjects were over 64 years old, married, White, at late stage of disease, and survived greater than 6 months after diagnosis.

Measures:

SDS, ESDS, CES-D.

Findings:

- Study subjects reported high levels of symptom distress, dependency, and depression at the time of hospital discharge. Scores did not differ remarkably when these patients were grouped according to timing of death.
- Remarkable differences were evident at the 3-month follow-up, with intense levels of symptom distress, dependency, and depression reported by the patients in the early-dying group.
- Home nursing care was characterized primarily as patient education intervention (43%). The remainder of the nursing care focused on providing psychological support and reassurance (16%), making needed referrals and activating community based support services (14%), assessing to identify patient problems and establishing nursing diagnoses (12%), and monitoring current physical and emotional status (19%).
- Although not significantly different, patients who died early might have received more intensive nursing care.
- Symptom distress was significantly correlated with the number of nursing interventions.
- Although not statistically significant, an inverse relationship was suggested between patients' symptom distress and depression and the number of teaching interventions they received.

29. Naylor, M.D., Brooten, D., Campbell, R., Jacobsen, B.S., Mezey, M.D., Pauly, M.V., & Schwartz, J. S. (1999a). Comprehensive discharge planning and home follow-up of hospitalized elders: A randomized clinical trial. *JAMA, 281*, 613-620.

Roles of the ESDS: as one of the outcome measures of the effects of a comprehensive discharge planning and home follow-up intervention.

Purpose:

Examine the effectiveness of an advanced practice nurse-centered discharge planning and home follow-up intervention for elders at risk for hospital readmissions.

Design:

Randomized clinical trial with follow-up at 2, 6, 12, and 24, weeks after index hospital discharge.

Sample:

A total of 363 patients with various medical and surgical problems. The mean age of the sample was 75 years. Fifty percent of the sample were men and 45% were black.

Measures:

Readmissions, time to first readmission, acute care visits after discharge, costs, ESDS, CES-D, Short Portable Mental Status Questionnaire, patient satisfaction.

Findings:

- By week 24 after the index hospital discharge, control group patients were more likely than intervention group patients to be readmitted at least one time (p<0.001). Fewer intervention group patients had multiple readmissions (p=0.01).
- The intervention group had fewer hospital days per patient (p< 0.001).
- Time to first readmission was increased in the intervention group (p< 0.001).
- At 24 weeks after discharge, total Medicare reimbursements for health services were about $1.2 million in the control group versus about $0.6 million in the intervention group (p< 0.001).
- There were no significant group differences in post-discharge acute care visits, functional status, depression, or patient satisfaction

30. Naylor, M., & McCauley, K. M. (1999b). The effects of a discharge planning and home fellow-up intervention on elders hospitalized with common medical and surgical cardiac conditions. *Journal of Cardiovascular Nursing, 14*, 44-54.

Roles of the ESDS: as one of the outcome measures of the effects of a comprehensive discharge planning and home follow-up intervention.

Purpose:

Examine the effectiveness of an advanced practice nurse-centered discharge planning and home follow-up intervention for elders at risk for hospital readmissions.

Design:

Randomized clinical trial with follow-up at predischarge (T1) and 2 (T2), 6 (T3), 12 (T4), and 24 (T5), weeks after index hospital discharge.

Sample:

A total of 202 patients with various medical and surgical problems. The mean ages of the medical sample were 76 and 77 years for intervention and control group, respectively, and for surgical sample was 73 years for both intervention and control groups. Fifty-four percent of the sample were men and 42% were black.

Measures:

Readmissions, total days of re-hospitalization, ESDS

Findings:

- Medical patients in the intervention group had fewer multiple readmissions during the 24 weeks of follow-up and a reduced total number of days of re-hospitalization.
- There were fewer hospital readmissions in the surgical group when measured from discharge to 6 weeks.
- There were no differences in functional status between intervention and control groups for either population.

31. Nuamah, I. F., Cooley, M. E., Fawcett, J., & McCorkle, R. (1999). Testing a theory for health-related quality of life in cancer patients: A structural equation approach. *Research in Nursing and Health, 22*, 231-242.

Roles of the ESDS: as one of the components of health-related quality of life (role function).

Purpose:

Test Roy Adaptation Model (RAM) propositions using structural equation modeling.

Design:

A secondary analysis of data from a longitudinal study of QOL of patients following surgical treatment for cancer.

Sample:

375 newly diagnosed postsurgical cancer patients 60 years and over. Nearly half of the sample were females. The majority of the subjects had early stage disease, were married or cohabitating, and were White.

Measures:

ESDS, SDS, CESD

Findings:

- The four response modes of the RAM (physiologic, self-concept, interdependence, and role function) were not interrelated.
- Severity of illness and adjuvant cancer treatment had the strongest association with the biopsychosocial responses and should be considered the focal environmental stimuli.

32. Ring, D., Perey, B.H., & Jupiter, J.B. (1999). The functional outcome of operative treatment of ununited fractures of the humeral diaphysis in older patients. *The Journal of Bone and Joint Surgery, 81A*(2), 177-190.

Roles of the ESDS: as one of the outcome measures of modified operative techniques of plate-and-screw fixation of the humeral diaphysis.

Purpose:

Investigate the effects of operative treatment of unsuited fractures of the humerus in older patients on functional independency.

Design:

Descriptive longitudinal follow-up study. The majority of patients had been followed up for an average of three years and one month.

Sample:

Twenty-two elderly patients who had an atrophic, unstable, ununited fracture of the humeral diaphysis. The average age of the subjects was 72 years. Half of the subjects had one or more major comorbidities.

Measures:

ESDS, Disabilities of the Arm, Shoulder, and Hand Questionnaire, Modified Scale of Constant and Murley.

Note: ESDS scores had been standardized to fit on a scale of 0 to 100, with higher scores reflecting greater enforced dependency.

Findings:

- The study subjects had significant improvements in all of the functional scores, including the ESDS, the Modified Scale of Constant and Murley, and Disabilities of the Arm, Shoulder, and Hand Questionnaire.
- There were no major post-operative medical complications occurred in this group of patients.

33. McCorkle, R., Strumpf, N. E., Nuamah, I. E., Adler, D. C., Cooley, M. E., Jepson, C., Lusk, E. J., & Torosian, M. (2000). A specialized home care intervention improved survival among older post-surgical cancer patients. *Journal of the American Geriatric Society, 48*, 1707-1713.

Roles of the ESDS: as one of the potential predictors of survival

Purpose: to compared the length of survival of older post-surgical cancer patients who received a specialized home care intervention provided by advanced practice nurses with that of patients who received usual follow-up care in an ambulatory setting and to identify predictors of survival.

Design: A randomized controlled intervention study.

Sample: Three hundred seventy-five patients aged 60 to 92, newly diagnosed with solid cancer. One hundred ninety patients were randomized to the intervention groups and 185 to the usual care group.

Measures: Time from enrollment of patients into the study until death, CESD, DSD, ESDS.

Findings:

- Twenty-two percent of patients in the specialized home care intervention died during the 44-month follow-up period, compared with 28% in the usual care group.
- The specialized home care intervention group was found to have increased survival.
- Among early stage patients only, there was no difference in survival between the intervention and control groups.
- Among late stage patients, there was improved survival in the intervention group. The relative hazard of death in the usual care group was 2.04 (CI: 1.33 to 3.12; p=0.001) after adjusting for stage of disease and surgical hospitalization length of stay.
- Late stage patients had a 4-fold increase in hazard of death compared with early stage patients.
- Age, race, depressive symptoms, symptom distress, and enforced social dependency at baseline were not predictive of the length of survival.

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